

Department of Medicine

Monday, August 08, 1994

Rev. Marge Ragona
Covenant Metropolitan Community Church
3001 Fourth Avenue South
Birmingham, AL 35205

Dear Marge:

Just a reminder about our AIDS Interfaith Prayer service on the third Monday night of the month (this coming Monday) from 7:30-8:15 p.m. for persons of all faiths. Rev. Larry Horne, pastor of Woodlawn United Methodist Church, will lead our meditation. As you probably know, we pray for persons who are infected or affected by HIV, we remember those who have died recently, we take time to thank God for the AIDS service organizations and health care professionals in our area by name, and finally we pray for congregations who are already involved and considering AIDS ministry.

Our meeting site for July-December is at St. Francis Xavier Catholic Church, just off Montclair Road directly across from the entrance to Baptist Montclair Hospital (there is a sign at the red light). It is very easy to find and we meet in the small, beautiful chapel. Our next meeting is this Monday night, August 15.

Upcoming meetings will be:

August 15

September 19

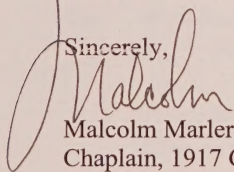
October 17

November 21

December 19

Thanks again for your interest and commitment to the many persons who are affected by AIDS in our community. May God's grace be yours.

Sincerely,



Malcolm Marler
Chaplain, 1917 Clinic

p.s. Congratulations on your calling to be the Senior Pastor at Covenant! They are fortunate to have you.



**Proposal to the
BAO Interfaith Committee
from Malcolm Marler,
Chaplain, UAB 1917 Clinic**

Introduction

Since I began my work at the UAB AIDS Outpatient Clinic, I made a commitment to avoid duplicating programs, groups, and committees among the AIDS organizations in Birmingham. We simply do not have the time, energy, or resources to reinvent the wheel because the need is too great.

As I plan AIDS training events for our churches and synagogues, I need a group to give me guidance to make sure we are addressing the needs of our faith communities. At first I considered forming an interfaith group of clergy and lay persons to help with this planning. But, it seems unwise to create a separate group when one already exists (i.e. the BAO Interfaith Committee). I have talked with Harry Wingfield, Karen Matteson, and Ruth Vann Lillian about the possibility of expanding the mission of this committee. I am willing to enlist additional clergy and lay persons to be involved in accomplishing the mission goals below. They have been supportive of the idea. Thus, I would like to make the following proposal and discuss it with you at a called meeting from 6:00-7:15 p.m. on Monday, May 16th at Pilgrim Congregational Church, 3801 Montclair Road.

Proposal

The BAO Interfaith Council expand its mission to include the following:

- 1) Communicate with all AIDS service organizations in greater Birmingham and explore ways local churches/synagogues can work with them more effectively.
- 2) Coordinate the monthly prayer service for persons with AIDS, family and friends with local churches/synagogues to get more participation from area churches.
- 3) Develop a resource pool of clergy who are willing to provide pastoral care to persons with AIDS who do not have a pastor, priest, or rabbi.
- 4) In consultation with the AIDS Chaplain at the 1917 Clinic, plan clergy and lay education events to equip faith communities to respond to the AIDS crisis with compassion, education, and ministry.

This expanded council would meet from 6:00-7:15 p.m. prior to the monthly prayer service on the third Monday of the month. However, if the agenda prepared ahead of time did not justify an hour and fifteen minute meeting, the group would be contacted and we would not meet. We may also want to consider a name change to be more inclusive of other organizations. I look forward to your response.



Digitized by the Internet Archive
in 2026 with funding from
CLIR DHC Grant 2026-2028

<https://archive.org/details/2174.02.38>

AIDS Interfaith Support Network

Next meeting is Monday, June 20, 6:00-7:15 p.m., Pilgrim Congregational Church, 3801 Montclair Road, preceding the prayer service from 7:30-8:00 p.m.

Summary of meeting on May 16, 1994

Sixteen persons were present.

A proposal was made by Malcolm Marler, AIDS Chaplain at 1917 Clinic, to expand the focus and vision of the Birmingham AIDS Outreach Interfaith Committee to relate to all AIDS service organizations and service providers. We want to become a bridge between AIDS organizations and the religious community. The proposal with slight amendments, is included with this report.

After brief discussion, the group agreed to accept the proposal and rename itself to the *AIDS Interfaith Support Network*. Focus groups will be formed according to a person's interest at the next meeting on June 20. The four focus groups will be: Communication with AIDS organizations and how congregations can meet some of their needs; Coordination of monthly prayer service for the greater Birmingham community; Development of a resource pool of clergy available to patients who do not have spiritual support; and Clergy/Congregational education events to enable communities to respond with compassion, education, and ministry.

A new educational program for clergy and lay persons was announced called *Friday Morning Grace* that will be repeated every Friday of the year at the UAB 1917 Clinic (908 South 20th Street, Birmingham). It is a good first step for individuals to learn about HIV/AIDS and how congregations can make a difference in the epidemic. Reservations are required by calling Malcolm Marler, 934-1917. There is no charge and a free brochure is available.

Harry Wingfield asked to have the Fall Retreat for persons living with HIV/AIDS on next month's agenda for discussion.

Joe Elmore has been employed by the 1917 Clinic to develop and coordinate AIDS Care Team Training for Congregations in greater Birmingham in cooperation with BAO, ATFA, AIM, and Baby's Place (and medical clinics and hospitals). He can also be reached at 934-1917. Kay Mutert is a summer intern developing an AIDS Ministry Resource Center for Congregations. An annotated bibliography will be available by the end of the summer.

The first statewide AIDS Ministry Conference in Alabama will be Thursday, October 20, 1994 in Birmingham. A planning team will be formed at our next meeting as a group.

Ruth Vann Lillian resigned her position on the council effective immediately as the Prayer Service Coordinator due to a move. Ruth was thanked for doing such an excellent job.

The new location for the Prayer Service (July - December) will be announced at the next meeting. Harry Wingfield believes his church building is possible and will check into it.

**Proposal to the
BAO Interfaith Committee
from Malcolm Marler,
Chaplain, UAB 1917 Clinic**

Introduction

Since I began my work at the UAB AIDS Outpatient Clinic, I made a commitment to avoid duplicating programs, groups, and committees among the AIDS organizations in Birmingham. We simply do not have the time, energy, or resources to reinvent the wheel because the need is too great.

As I plan AIDS training events for our churches and synagogues, I need a group to give me guidance to make sure we are addressing the needs of our faith communities. At first I considered forming an interfaith group of clergy and lay persons to help with this planning. But, it seems unwise to create a separate group when one already exists (i.e. the BAO Interfaith Committee). I have talked with Harry Wingfield, Karen Matteson, and Ruth Vann Lillian about the possibility of expanding the mission of this committee. I am willing to enlist additional clergy and lay persons to be involved in accomplishing the mission goals below. They have been supportive of the idea. Thus, I would like to make the following proposal and discuss it with you at a called meeting from 6:00-7:15 p.m. on Monday, May 16th at Pilgrim Congregational Church, 3801 Montclair Road.

Proposal

The BAO Interfaith Council expand its mission to include the following:

- 1) Communicate with all AIDS service organizations and medical facilities in greater Birmingham and explore ways local congregations can work with them more effectively.
- 2) Coordinate the monthly prayer service local congregations to maximize participation..
- 3) Develop a resource pool of clergy who are willing to provide pastoral care to persons with AIDS who do not have a pastor, priest, or rabbi.
- 4) In consultation with the AIDS Chaplain at the 1917 Clinic, plan clergy and lay education events to equip faith communities to respond to the AIDS crisis with compassion, education, and ministry.

This expanded council would meet from 6:00-7:15 p.m. prior to the monthly prayer service on the third Monday of the month. However, if the agenda prepared ahead of time did not justify an hour and fifteen minute meeting, the group would be contacted and we would not meet. We may also want to consider a name change to be more inclusive of other organizations. I look forward to your response.

by the group reviewing and revising the resources according to their experiences. They are resources developed over time and are open to modification to fit the particular needs of the group.

The two articles in the **Family Network** section explore how support groups have helped two individuals who have had family members diagnosed with HIV. Richard Cory, husband of a woman with HIV and father of a boy with AIDS, tells how he found a support group that met his needs in *Faith, Hope, and Commitment*.

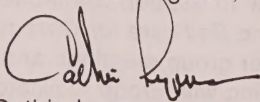
Anne Grant, a group facilitator for Kairos House in San Francisco tells an all too familiar and frequent story of the experience of one mother who found support not only among "strangers" in a support group, but also, those who loved and cared for her son. Kairos House is a non-profit service offering non-judgmental, confidential help to parents, friends and loved ones of AIDS-affected persons, as well as support to medical, nursing and other professional caregivers.

One of the most frequently requested resources within this ministry is a list of resources, books, videos, etc. about HIV/AIDS ministry. As part of the research for these last three **Focus Papers**, we have put together an annotated bibliography which we hope will be useful in your ministry with persons living with HIV/AIDS. If there are resources not listed that you are aware of, please let us know about them. If any of these are particularly not helpful, please let us know.

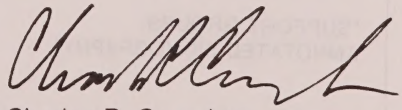
CAM continues to be a major resource for those affected by HIV/AIDS, with more than 400 users. If you haven't done so, we invite you to try it by using your computer and modem to dial 1-212-222-2135.

Special thanks goes to the Reverend Dr. Nancy Carter for her work on this **Focus Paper** and continued work as the sysop of CAM.

With kindest regards,



Cathie Lyons
Associate General Secretary



Charles R. Carnahan
Executive for HIV/AIDS Ministries

AIDS, A FAMILY THERAPIST'S POINT OF VIEW

by Dr. Robert Perelli, CJM

Note: Support groups often operate much like families. The following article, which looks at HIV and family dynamics, may be a helpful resource for facilitators of HIV support groups.

Reprinted from Kairos News (Spring 1994), Volume 4, Number 30. You may reproduce any part of Kairos News as long you give the newsletter and any author, the credit.

A person living with HIV/AIDS needs the acceptance and support of his or her "family," whether it is a family of origin, a family of choice, or a combination of the two. However the diagnosis of HIV/AIDS can become a family crisis and everyone involved may need help in working through that crisis.

In dealing with a family crisis, traditional one-on-one therapy limits us to one person's point of view. A valuable alternative is to think "systemically" -- that is to approach the "family" as a system. Family Systems Theory is one such systematic approach.

Have you ever observed someone who seemed to have unresolved emotional attachment to their family-of-origin? No matter how much they deny it or pretend to be separate from their family-of-origin, they appear to be still "stuck to" the members of their family and that "stuck togetherness" still continues to operate in the background of all their relationships.

As a child that person may have been "selected" from among their siblings by virtue of some difference-- by being a member of a sexual minority, for example-- and they may become caught in an intense emotional triangle in their family of origin while other siblings are spared. The triangle is intensified when the

person has a life threatening disease like AIDS.

Brian's situation is a good example. Brian, a 28-year old gay man, was given a poor prognosis by his physician and came into therapy to deal with the stresses of his illness. Since his life expectancy was rather short, one of his primary concerns was living in the present. Fortunately, Brian was quick to learn that the biggest obstacle to living in the present was not just his illness, but his function in his family of origin. That function was aggravated by the fact that he had to move back into his parents' home which he had left years before.

As Brian described his family, it became more and more apparent that he was caught between a rock and a hard place. Over the years his father had become more and more distant from the family. The excuses were typical: he had to work overtime; he was tired; he lost interest in his adult children's lives. An introvert by nature, Brian's father spent more and more time by himself, reading the paper, fishing or watching sports on TV. Brian realized that his father's distancing had been going on for years. An only child, Brian's father had little facility with children and often felt jealous of the attention his children received from their mother.

Brian's mother, on the other hand, became the perfect mother. She was intimately involved with all her children's lives: she ran the youth group at church, she volunteered as a den mother when her boys were in Cub Scouts; she was the president of the PTA. Every time Brian's father "solved" a family problem with distance, Brian's mother countered with closeness.

Now that Brian and all his siblings were adults, Brian's father thought that he would finally be able to spend some quality time with his bride. In planning his coming retirement, he dreamed of traveling across Europe with his

wife. However, Brian's mother resented her husband's distance from his children, both in the past as well as in the present. She struggled to stay very involved with her adult children despite the geographical distance that separated her from them. Then Brian became sick and moved home. The vacuum created by the "empty nest" syndrome and exacerbated by her husband's distance was soon to be filled in by Brian. It wasn't long before Brian, the youngest of three male children, was "triangled" between his mother and father.

Brian is struggling to extricate himself from the triangle between his father and mother. Although Brian is forced to live at home for financial reasons, he spends a significant amount of time traveling. He sets aside a portion of his disability checks so that whenever he is feeling well enough he can seize the opportunity to visit his brother in Atlanta or his ex-lover in Washir, gton.

Another way Brian struggles to keep himself out of the triangle with his parents is the way he

manages his medical care. Despite his mother's prompting, Brian is opposed to chemotherapy treatments for an AIDS-related illness and has made a decision not to pursue that course of treatment. He feels that he is opting for quality time rather than quantity time. His physician respects his decision and his sister-in-law, who has been appointed health care proxy, understands his wishes.

The third way Brian is dealing with his family of origin is in the realm of spirituality. Although Brian comes from a devout Christian family and despite the fact that his brother and his sister-in-law are both ordained clergy, Brian has definite ideas about his funeral. Brian will be buried from a nondenominational church and his brother will not conduct the service. Brian wants his brother to be able to grieve his death rather

than having to assume the responsibility of pastoring the family. Furthermore, as a gay person who never felt particularly valued by mainline religions, Brian feels more authentic in this decision.

When it comes to the issues of travel, medical treatments, and spirituality, Brian tries very hard not to argue or debate these topics with his family. He realizes that reacting to their displeasure would only locate him back in the triangle. By the same token, silence, withdrawal or running away from the family are the kinds of reactions that stunt emotional growth. As a matter of fact, they are the kind of reactions that Brian's father still uses to manage his relationships in this family.

By avoiding either extreme, Brian can accomplish a variety of goals. First, he can live his life as he wants to and, with some effort on

the part of his parents (they are now in couple's therapy), do this without losing his family. Also, by

changing his function in the family, he invites his parents to outgrow some of their less healthy behavior and become a functional couple. And lastly, he can preserve the emotional energy he needs to deal with his own mortality. He may very well die a happy death and thereby make it easier for his parents and siblings to grieve his loss as a family.

Dr. Robert J. Perelli, CJM, is a psychotherapist and founder of AIDS Family Services, a community-based agency providing psychological services to individuals and families in Buffalo, New York. Dr. Perelli serves as a consultant for AIDS Community Services, Children's Hospital, Hospice/Bufallo, and the Hemophilia Center. He has written a book and numerous articles on family issues surrounding HIV and, as a Roman Catholic priest, serves on the Interfaith AIDS Network of Western New York.

A person living with HIV/AIDS needs the acceptance and support of his or her "family," whether it is a family of origin, a family of choice, or a combination of the two.

Ten Characteristics of a Healthy Group

The 10 items named below are guidelines, not rules. An effective group:

1. ***large enough to have a variety*** of persons with different backgrounds and viewpoints but ***small enough for everyone to have time to share*** (usually 5 to 15 people);

2. ***shares the leadership and responsibility*** for the work of the group, even if the group has a designated leader or facilitator;

3. ***has a defined purpose and establishes group guidelines and boundaries***, including the creation of an atmosphere of respect and support, which is to be demonstrated toward all members of the group;

4. ***regards all members as whole people, created in the image of God*** and treats people as sacred;

5. ***starts with a plan or an agenda and a time frame but is flexible*** and can change the focus of discussion or the length of the meeting by consensus, if an unanticipated and important concern is raised;

6. ***practices democracy***, permits individuals to fully contribute to discussions and take the time needed to participate in group decision-making;

7. ***encourages "quiet" people*** to talk, while realizing that verbal contributions are not the only indicator of a valuable group member;

8. ***supports communication and problem-solving***, taking appropriate steps, including having a standard process for dealing with conflict, to lessen hostility, ill-feelings, or misunderstandings that may arise among members;

9. ***has a sense of humor and the gift of healing laughter*** as it celebrates life, even in the midst of serious situations;

10. ***takes time to get feedback*** from group members about their thoughts and feelings at different times during the meeting, including at the end of a session.

TEN CHARACTERISTICS OF A HEALTHY GROUP

1. ***large enough to have variety***

2. ***shares the leadership and responsibility***

3. ***has a defined purpose, group guidelines and boundaries***

4. ***regards all members as whole people, created in the image of God***

5. ***start with a plan or agenda and a time frame but is flexible***

6. ***practices democracy***

7. ***encourages "quiet" people***

8. ***supports communication and problem-solving***

9. ***has a sense of humor and the gift of healing laughter***

10. ***takes time to get feedback***

How to Support Someone Who Is Grieving

1. **Take the initiative.** Make contact even when you are not sure exactly what is needed. Grievers often have trouble knowing what they need and asking for it.

2. **Offer something specific.** Nothing is too small to do. A pastor reports how a parishioner provided a valuable ministry by polishing the shoes of a grieving woman's children. A woman who lost a child tells how she woke up one morning to find an elderly neighbor mowing her lawn and pulling weeds. Ask questions such as: "Can I go to the grocery store for you? Do you want me to pick you up for church (or to the gym, or to a 12-step meeting, etc.)? Would you like me to bring you some of my famous (name a dish you like to make) for supper? Do you need help cleaning your house?"

3. **Be honest.** Offer to do only what you want to do and are prepared to do. Express your real feelings. If you feel helpless, admit it.

4. **Help the griever share memories.** Don't avoid mentioning the name of the person who has died. Share a memory you have of the person. Gently ask the griever to talk about the loved one.

5. **Communicate non-verbally too.** A sympathetic look, a touch or embrace, or sitting with a person quietly can be healing. Be sensitive to the fact that some people are uncomfortable with touching; do not push them into accepting touch. Ask, "Would you like a hug?"

6. **Beware of using simplistic statements that may suggest the griever repress her/his feelings or that God willed the death of the person.** Examples include: "It was for the best"; "Don't cry; be strong"; "God took him/her" (this statement scares children); "Time heals." Instead encourage the griever to express her or his feelings. Ask open-ended questions about what is happening in the griever's life these days.

7. **Do not assume that you know what is right for the griever.** Check out what the griever wants before doing something for him or her. Do not tell the griever, "You must do this" or "You have to do it this way." Ask how the griever feels, what the griever wants to do. Just because something has helped you or others, does not mean it will help this person.

8. **Encourage the griever to participate in meaningful rituals.** Ideas vary with the individual: make meals at the same time, take daily walks with a friend, read from the Bible or devotional book every day,

HOW TO SUPPORT SOMEONE WHO IS GRIEVING

1. **Take the initiative.**

2. **Offer something specific.**

3. **Be honest.**

4. **Help the griever share memories.**

5. **Communicate non-verbally too.**

6. **Beware of using simplistic statements that may suggest the griever repress her/his feelings or that God willed the death of the person.**

7. **Do not assume that you know what is right for the griever.**

8. **Encourage the griever to participate in meaningful rituals.**

9. **Share information about appropriate support resources.**

10. **Recognize that grieving is a process.**

go to regular group gatherings, make Friday night go-to-the-movies night with a friend. One-time rituals such as planting a tree in memory of the loved one can also be healing. Rituals help to re-establish needed structure.

9. **Share information about appropriate support resources.** Resources can include written material, videos, support groups, professional counselors, legal advisors, church groups.

10. **Recognize that the grieving process takes different lengths of times for people, depending on their personality, their emotional attachment to the person who died, and the circumstances of the death.** Do not put your own time line for grieving onto someone else. The average grieving process is two years. Some situations, such as suicide, sudden death, or catastrophic loss may take longer. Be prepared to stand by the griever as long as needed.

Self-Care For Caregivers

SELF-CARE FOR CAREGIVERS

1. **All helpers are grievers.**

2. **Set boundaries.**

3. **Primarily play a listener/facilitator role.**

4. **Recognize when the griever needs professional and refer the person to an appropriate resource.**

5. **Get appropriate support for yourself.**

1. **All helpers are grievers.** You may also be grieving the loss of the same person, or of one or more others in your life. Recognize your own vulnerabilities and when you may be projecting your own feelings on the griever. Do not use the griever to help your own grieving process. Though helping another may also help your grief, this is not to be your goal when you are in the helper role.

2. **Set boundaries.** Before you commit yourself to a griever, assess how much time you can give and what kind of support you are able to give. Promise only what you can deliver. If you need to change boundaries in process, tactfully and honestly discuss this with the griever.

3. **Primarily play a listener/facilitator role.** Encourage the griever to take healthy steps without fostering dependency on you. If the griever senses that you want control or run her or his life, the griever may not feel free to share with you some of the most important things that are going on.

4. **Recognize when the griever needs professional help beyond your training and refer the person to appropriate persons.** Take discussions of suicide seriously. Make a pact with the person that she or he will not hurt herself. Firmly but gently guide the person to a professional. If the person has legal problems related to a will or the funeral, assist the person in finding appropriate help.

5. **Get appropriate support for yourself.** Talk with friends, family, therapists, support groups. Have your own support system to deal with issues that come up around your helper role and your own grieving process.

"AIDS Ministry," I asked her to put me in touch with this person so that I could share the HIV information that I collect for others and hopefully help them too.

By the time I joined Rebecca's group, they had already been meeting for several months without the official recognition of the church. After attending the group just once, I found that a very serious void had been filled. I shared my family's story and my concerns and heard similar concerns from others. Then I didn't feel as alone. I have received a lot of support from computer bulletin board systems such as the Computerized AIDS Ministry (CAM) and the AIDS Education and General Information Service (AEGIS), but these services do not provide the same kind and level of support as face-to-face human contact.

Although this HIV support group was started by and for Christians, no one attempts to preach religion to the members. This is

very important as many people who are not of the same faith or denomination might find this offensive. And yet, the ministry of the church is still spread. Not through preaching and words, but through actions and example which carries a much stronger message. Yes... the church can play an important role in support groups through the emotional and spiritual support they provide and spread the Christian ethic through example.

Shortly after I began to attend, Rebecca and her family announced the existence of the group during Sunday services at the Presbyterian Church where they are members. As Rebecca told the story of

her brother, the congregation was noticeably moved. Tears were shed, including my own. The day of her announcement was the first time I had attended church in years. I was impressed and affected by the genuine love and support that I witnessed.

My son Alex also went with me. He knows that he has AIDS and has told friends and neighbors on a few occasions that he has AIDS, despite us telling him he should not. We are concerned that he may face hatred and rejection from people that do not understand AIDS. I took him with me that day because I wanted him to realize that he and his mother are not alone-- that there are other people who have HIV/AIDS and that there ARE people who truly care.

Yes...the church can play an important role in support groups through the emotional and spiritual support they provide and spread the Christian ethic through example.

Rebecca and her family and the other members of this group have touched me and affected my life in a way I didn't know was possible. I feel less alone, less cynical, more hopeful, and more at peace with my situation than

I ever have since this ordeal began. I can't begin to thank these people enough for what they have unselfishly done for me. HIV/AIDS support groups are clearly an area where the church can play a pivotal role.

Richard B. Cory lives in Chesapeake, VA. He is an American Red Cross certified HIV/AIDS Instructor and a member of the National Association of People with AIDS (NAPWA).

U.M. FAMILY HIV/AIDS NETWORK

A NETWORK OF UNITED METHODIST FAMILIES AND
OTHERS WHO HAVE BEEN TOUCHED BY HIV/AIDS

Faith, Hope, and Commitment A Participant's Perspective on Support Groups

By Richard B. Cory

In mid-1988 my wife, Catherine, went to the Red Cross to donate blood. A year and a half earlier, she had received a transfusion after giving birth to my son, Alex. She felt obligated to give back some of what she had received.

A couple of weeks later the Red Cross asked her to come into their office. That's when we found out that she was infected with HIV. A short time later, we found out that Alex was also infected, presumably as the result of breast feeding. In December 1992, Alex was diagnosed to have AIDS.

In the years after Catherine and Alex were diagnosed, people invited me to attend HIV support groups many times. However, I never joined a support group until late 1993. At first, like so many others, I was afraid:

- afraid to admit that my family was affected and infected.
- afraid of being associated with anything to do with HIV or AIDS.

Then, after talking to the facilitator or members, I found that the groups that were available in my area fell short in several areas I was looking for... faith, hope, and commitment.

I have observed that many HIV support groups seem to be devoid of faith and

hope. The underlying theme of the meetings is sickness and death. This characteristic, at least for me, is far from supportive. Meetings seem to drag the members deeper into hopelessness and despair, rather than lifting them up.

I have a friend who went through some of these same things when trying to find an HIV support group. Her brother has AIDS. She had noted the lack of commitment among members of support groups she attended. The "support" from the group

At first, like so many others, I was afraid:

- ***afraid to admit that my family was affected and infected.***
- ***afraid of being associated with anything to do with HIV or AIDS.***

was only when the group met. Many members chose to remain nameless. Members seldom or never contacted each other outside of the meetings. So, my friend Rebecca, started a support group to fill these voids.

When I first contacted Rebecca, I was not looking for a support group. I have a friend at work, Mary, who knew of my family's situation. When Mary told me that someone at her church was starting an

A Mother's Story

By Anne Grant

Reprinted from Kairos News (Spring 1994), Volume 4, Number 30. You may reproduce any part of Kairos News as long you give the newsletter and any author, the credit.

A mother visiting from a small town in the midwest recently attended the Family Group at KAIROS for the first time. Her story was a story I have heard many times since the group began.

She had received a call that her son had been hospitalized and felt she needed to be with him. Her husband was having a difficult time dealing with his son's homosexuality let alone his AIDS diagnosis, so although she had never traveled alone, she made the trip without him. She didn't know any other person who was openly gay and she had never been to San Francisco before or met any of her son's friends.

However her apprehensions were quickly dispelled. She was surprised at how quickly she was accepted by his partner and their circle of friends and she was impressed by the loving support her son was receiving from all of them. For those who were estranged from their families, she soon became "Mom."

She talked about how much she had changed since she arrived. Caring for her ill son was physically and emotionally draining to be sure, but she felt honored that he was allowing her to care for him. She also felt she was learning something about herself and her relationship to her son. She spoke, as many family members

have done, of feeling enriched by the experience. And while it is still difficult to accept her son's illness, she knows that she will be less afraid to talk about it with other family members and friends when she goes back to her home community.

Anne Grant, PhD, is a Grief Counselor and Family Group Facilitator for Kairos House in San Francisco, California.

CALL-A-MOM: MOTHERS' HOTLINE

Call-a-Mom is a hotline where mothers can telephone to talk with other mothers of people with AIDS sponsored by People with AIDS Coalition New York.

1-800-828-3280

*Monday / Wednesday / Friday 2-6 pm
Eastern Time*

SUPPORT GROUPS: ANNOTATED BIBLIOGRAPHY

Compiled by Nancy A. Carter, M.Div., Ph.D, from her own library, the resource database on CDC NAC Online bulletin board service (adapted), and Focus: A Guide to AIDS Research and Counseling (December 1993), and AIDS Book Review Journal (shortened reviews by H. Robert Malinowsky). The Centers for Disease Control and Prevention (CDC) National AIDS Clearinghouse makes available the following information as a public service only. Reproduction of CDC NAC Online materials is encouraged; however, copies may not be sold, and the CDC Clearinghouse should be cited as the source of this information. Copyright 1994, Information, Inc., Bethesda, MD. All materials in the AIDS Book Review Journal are subject to copyright by the Board of Trustees of the University of Illinois and may be reprinted or redistributed for the noncommercial purpose of scientific or education advancement granted by Sections 107 and 108 of the Copyright Revision Act of 1976.

Counseling, Therapy, Pastoral Counseling

A Time for Caring: A Pastoral Approach to Persons with AIDS.

A 37-minute color video produced by the Lazarus Project in cooperation with the West Hollywood Presbyterian Church. Shares the stories of several active church members with AIDS. Includes their reflections on the kind of help they found most useful and comforting. Also includes a moving segment in the hospital as a man speaks of his faith with his pastor. Available for sale only; \$23 includes postage and handling. Make checks payable to The Lazarus Project, West Hollywood Presbyterian Church, 7350 Sunset Blvd., Hollywood, CA 90046.

Clinebell, Howard. *Basic Types of Pastoral Care and Counseling: Resources for Healing and Growth*. Revised and Enlarged. 1966; rpt. Nashville: Abingdon Press, 1984. 463 pp.

This book is a long-time basic resource for pastoral counseling. Some key chapters in relation to support groups are, "A Holistic Liberation-Growth Model of Pastoral Care and Counseling," "Facilitating Spiritual Wholeness," "Crisis Care and Counseling," "Bereavement Care and Counseling," "Group Care and Counseling," and "Training Lay Persons for Their Caring Ministries." (N. Carter)

Dane, Barbara O. and Samuel O. Miller. *AIDS: Intervening with Hidden Griefers*. Westport, CT: Auburn House/ Greenwood Publishing Group, 88 Post Road West, Westport, CT 06881, 1992. 225 pp.

Unfortunately little is written about the grieving process that goes on after a loved one has died. That is what this book is about. "Sadly the denial of grief goes hand-in-glove with the denial of death." The second decade of AIDS will bring more and more deaths and more and more individuals will

need counseling because of their losses to AIDS.... [The book] is written for mental health professionals and anyone who counsels those who are bereaved.... "AIDS is a family problem that transcends illness and death. It is uniquely one that causes families to feel they have failed and have a skeleton in the closet." Guilt, cultural and religious values, and burnout are all topics that are covered in one or more of the chapters. This would be a highly recommended book for public, medical, and academic libraries. (H. Robert Malinowsky)

HIV/AIDS Ministries Network, *Focus Paper #22*, focus on pastoral counseling; *Focus Papers #23 and 24*, focus on support groups.

Health and Welfare Ministries Program Department
General Board of Global Ministries
The United Methodist Church
475 Riverside Drive, Room 350
New York, New York 10115

Hoffman, Patricia. *HIV/AIDS Ministry: A Practical Guide for Pastors*. New York: Health and Welfare Ministries, 1993. 60 pp.

The Service Center
General Board of Global Ministries
7820 Reading Road, Caller No. 1800
Cincinnati, OH 45222-1800
Price: \$5.95 plus postage and handling.

An introduction to pastoral counseling/visitation with persons with HIV. Includes a valuable chapter, "Stories from the Epidemic," in which persons tell their own stories of how HIV has affected their lives, as persons who are HIV positive and as loved ones of those who are HIV positive. Another chapter explores "Ideas for Ministry." Also includes worship resources and an annotated bibliography. (N. Carter)

Hynson, Diana and Carmen M. Gaud. *To the Point: Confronting Youth Issues--AIDS*. Nashville: Abingdon Press, 1993.

This important resource offers practical ways to talk to teens and adults about AIDS in a biblical and theological context. It has materials in both English and Spanish. It also contains leader's guides for using Magic Johnson's book. Order from Cokesbury, 1-800-679-1789.

Land H., ed. *AIDS: A Complete Guide to Psychosocial Interventions*. Milwaukee, WI: Family Service American, Inc., 1992. 300 pp.

The book is an introduction to this broad topic. Two chapters on caregivers give information on

burnout, stress, and grief. A chapter on people of color and HIV is especially valuable. It focuses on Latinos, African Americans, Pacific Islanders, and Haitians. A strength of the book is its describing the many populations that are affected by HIV and how services must be tailored to each different group.

Landau-Stanton, J. and Clements, C. D. *AIDS, Health and Mental Health*. New York: Brunner/Mazel, 1993. 370 pp.

A primary source book for health care practitioners and people providing support to HIV positive people and their loved ones. Included in the book are discussions of how to deal with delirium or dementia, a multigenerational therapeutic approach, spiritual issues, and cultural diversity. It proposes a non-judgmental and supportive approach to the individual in his or her context.

Perelli, Robert J. *Ministry to Persons with AIDS: A Family Systems Approach*. Minneapolis: Augsburg-Fortress, 1991. 112 pp.

"The focus of this book will be on the crisis of AIDS in the male homosexual community." Although this is the focus, the counseling strategies can also be used for other individuals. Perelli makes a point that the church has to have compassion for the gay male even though the Bible and Christian doctrine teach that these individuals are disordered and that being gay is immoral. By discussing such topics at the emotional stresses of AIDS, system of psychosocial stressors, family systems theory, and the applications of this theory, Perelli makes a good contribution "to improving the ministry and quality of pastoral care to people with AIDS." This should be a must-read book for all ministers, regardless of their faith. (H. Robert Malinowsky)

Schaefer, Dan and Christian Lyons. *How Do We Tell the Children?: Helping Children Cope When Someone Dies*. 1986; rpt. New York: Newmarket Press, 1988. 145 pp.

This book is a step-by-step guide to talking about death with children of all ages, from age two through the teen years. It gives insights into what children think and understand, how they feel, and how adults can help them cope with those feelings. It also has a 16-page crisis guide that outlines the points in the book and contains sample "scripts" to help parents talk about life situations such as terminal illness, suicide, and AIDS. A good resource for dealing one on one with children. In cities such as New York where so many children are seeing loved ones die from AIDS, some support groups for children dealing with HIV deaths exist (and also support groups for HIV positive children). These are most likely to be run by professionals. (N. Carter)

Shelby, R.D. *If a Partner Has AIDS: Guide to Clinical Intervention for Relationships in Crisis*. New York: Harrington Park Press, 1992. 267 pp.

The author interviewed social service providers and 32 gay men for this book. It is helpful to understand relationship issues between white gay male couples who are financially comfortable. All

but three of the 32 men interviewed were white and none were suffering financially.

Shelp, Earl and Ronald H. Sunderland. *AIDS and the Church: The Second Decade*. Revised and Enlarged. Louisville, KY: Westminster/John Knox Press, 1992. 238 pp.

The book and its original edition are probably the best-known and most basic resource on AIDS and the church. Key chapters include, "Clinical and Psychosocial Effects of HIV/AIDS," "Illness in Christian Perspective," "God and the Poor," and "HIV/AIDS Ministries."

Threads of Love: A Tapestry of Remembrance.

A moving ten-minute video produced by Health and Welfare Ministries, GBGM, UMC, about the NAMES Project AIDS Memorial Quilt, showing the quilt and individual panels made in remembrance of persons who have died from AIDS. A good resource to open up discussion about grief over the death of loved ones from AIDS and to inspire people to make a quilt panel as a concrete means of working through grief and memorializing one who has died. Specify English or Spanish. The cost is \$12.00. The video is also available from the Service Center (#1713); see address above. (N. Carter)

Thompkins, Floyd Jr. *By the Pool of Bethesda*. Pompano Beach, FL: Genesis 1:26, 1992. 108pp.

Genesis 1:26
1000 NE 26th Ave.
Pompano Beach, FL 33062.
Price: \$6.95

This is a "unique and provocative collection of Christian reflections concerning terminal illness" with the last two chapters being "testimonies of hope and a tribute to those who have suffered from the disease of AIDS." Based on sermons given by Reverend Floyd Thompkins, Jr., this book offers spiritual comfort to all who read it. He uses his black preaching rhythm and style to come to grips with terminal illness, regardless of the cause. His main purpose for publishing this book is to show that there is a need for a Christian message that can bring hope to those who have a terminal illness such as AIDS. It would be an excellent book for any religious counselor and a must for those who think that AIDS is God's judgment. (H. Robert Malinowsky)

Support Groups

Barouh G. *Support Groups: The Human Face of the HIV/AIDS Epidemic*. Huntington Station, NY: Long Island Association for AIDS Care, Inc., 1992. 91 pp.

Long Island Association for AIDS Care, Inc.
P.O. Box 2859
Huntington Sta., NY 11746.
(516) 385-2451.

This manual uses personal stories from nine individuals to introduce the different types of HIV support groups conducted by the Long Island Association for AIDS Care. Guidelines on conducting the different types of support groups are included. Groups include the Human immunodeficiency virus (HIV) Forum, a 4-week introductory workshop; Persons with AIDS (PWAs); PWAs with substance-abuse problems; families, caregivers, and friends; bereaved families, caregivers, and friends; partners and spouse; bereaved partners and spouse; and facilitator. The model proposed by this book comes differs from some support group models. For example, one of the guidelines is no "cross-talk." Many support groups have gained much learning and growth from cross-talk, challenge, and disagreement done in a constructive way. Some reviewers are critical of the fact that only the 12-step model is used.

Bereavement Support Groups: Leadership Manual. 4th Edition. Denver, CO: Grief Education Institute, 1992. 162 pp.

Grief Education Institute
1780 S. Bellaire St., Ste. 132
Denver, CO 80222.
(303) 758-6048.

This manual includes activities for grief support groups. The first part of the manual gives background information and presents theories about grief from such experts as Sigmund Freud, Erich Lindemann, and Elizabeth Kubler-Ross, then looks at grief and growing. Part Two provides guidance for conducting support groups; and Part III outlines support group sessions. (Information from this manual may be useful to those who have lost a loved one AIDS.)

Dietz, S. D. and J. P. Hicks. *Take These Broken Wings and Learn to Fly: The AIDS Support Book for Patients, Family, and Friends*. Second Edition. Tucson, AZ: Harbinger House. 153 pp.

Harbinger House
2802 N. Alvernon Way
Tucson, AZ 85712.
(602) 326-9595.

This manual addresses the impact AIDS makes on the lives not only on those people infected by

HIV, but also on their families, friends, and caregivers. After briefly providing background information on the disease, the manual stresses that PLWAs need support to cope with their illness: Support from their families, support from their friends, support from their health professionals, and support from within. It outlines the normal feelings, such as fear, rejection, and doubt, that arise from a diagnosis of AIDS, and outlines strategies for coping with these feelings. The authors urge PLWAs to seek help through counseling, support groups, and to those who feel so inclined, the church. The manual stresses that those who make positive changes in actions and attitudes, and remain involved in the lives and activities of others, will experience an improved quality of life.

Dobihal, Edward Jr. and Charles William Stewart. *When a Friend Is Dying: A Guide to Caring for the Terminally Ill and Bereaved*. Nashville: Abingdon Press, 1984. 224 pp.

I often used this book, along with a resource book I had received at a training event sponsored by Shanti San Francisco, in the early years in the AIDS crisis when our church was preparing to sponsor a bereavement support group for those who had lost loved ones to HIV. It contains basic information on death, dying, bereavement but, more important for the topic of this focus paper, chapters on "Training the Laity for a Caring Ministry: A Training Module" and "Outline of a Death and Dying Seminar." (N. Carter)

Hay, Louise. *The AIDS Book: Creating a Positive Approach*. Santa Monica, CA: Hay House, 1988. 276 pp.

This book is based on Louise Hay's work in her weekly support group and contains real life experiences of people with AIDS. This book and other resources by Hay have been important to many people who are HIV positive, particularly white gay men. Each chapter begins with an affirmation. Affirmations are an important part of self-healing, according to the book. A chapter "Support Systems" contains a short list "How to Start a Support Group." The type of group proposed probably closest to "type 2" described in this paper, though many 12-step groups ("type 1") have incorporated Hays' ideas too. (N. Carter)

Kasl, Charlotte. *Many Roads, One Journey: Moving Beyond the 12 Steps*. New York: HarperCollins, 1992. 430 pp.

Charlotte Kasl, a Quaker feminist addiction expert, confronts the mystique that has built up around 12-step programs and concepts of addiction and codependency. She gives historical information that the 12-step model was created by white upper middle class men for white upper middle class men using the structure of a Christian fundamentalist group called the Oxford Group. Though many have found 12-step groups helpful, countless others, especially women, African-Americans, and Native Americans, find that these groups' emphases on conformity, humility, and personal failings works against their needs for self-affirmation and community support in overcoming issues of child abuse, sexism, racism, poverty, and homophobia. Kasl is eclectic and not everything "holds together" in this book but I think it is an important book. For the purposes of this AIDS Focus Paper, see especially "Healthy Groups, Dysfunctional Groups: How to Know the Difference" and "We Gather Together:

Finding or Forming a Group That Fits." (N. Carter)

Kirkpatrick, Bill. *AIDS: Sharing the Pain*. Cleveland: Pilgrim Press, 1990.

Pilgrim Press
700 Prospect Ave.
Cleveland, OH 44115
216-736-3700

Price: \$9.95 plus \$2.50 shipping.

Contains practical guidelines especially helpful for clergy and lay caregivers.

Pohl, Mel, Deniston Kay, and Doug Toft. *The Caregiver's Journey: When You Love Someone with AIDS*. San Francisco: Harper/Collins, 1991. A Hazelden Book. Order from Harper/Collins or Hazelden, Pleasant Valley Rd., Box 176, Center City, MN 55012. Phone: 1-800-328-9000. The cost is \$10.00 plus \$3.50 for orders up to \$25.00.

Addressing the special needs of caregivers, this book helps friends, family members, and health care professionals work through their feelings, develop tools for acceptance, and understand the common stages in caring for those who are HIV positive. Written from a 12-step perspective.

Qwackebush M., J.D. Benson, and J. Rinaldi. *Risk and Recovery: AIDS, HIV and Alcohol*. San Francisco: UCSF AIDS Health Project, 1992. 242 pp.

A comprehensive guide for addressing HIV-related concerns in alcohol treatment settings using the 12-step tradition as a basis. The book avoids technical language, making it readable.

Williams, Cecil. *No Hiding Place: Empowerment and Recovery for Our Troubled Communities*. San Francisco: HarperSanFrancisco, 1990. 228 pp.

This book describes the support groups model used by Glide Memorial United Methodist Church in San Francisco. It critiques the 12-step model. Williams says: "When people declared that the Twelve Steps were the only way to become drug-free, it sent a message to blacks: There is nothing missing from the Twelve Steps; something must be wrong with you.... "The Twelve Steps focus on individual recovery, as if independently getting clean and sober were the ultimate goal. But African Americans are a communal people--we fight for our freedom together.... These programs teach people to get clean and sober and to go back out into mainstream society. Well, the only society many of our folks needing recovery know is the drug mix--they've never been in mainstream.... As long as blacks, women, and poor people remain anonymous, they remain invisible and unheard.... To us, anonymity feels like a place to hide. We believe there is no hiding place in recovery. We must open up and stand together" (pp. 8-9). (N. Carter).

You Are Not Alone: National Lesbian, Gay And Bisexual Youth Organization Directory. New York, NY: Hetrick-Martin Institute, 1993. 59 pp.

Medical Writing and Clinical Data Services, Incorporated
50A Commercial St.
Provincetown, MA 02657.
(508) 487-4099.

This directory aims to furnish youth-serving professionals and young people with a list of organizations that provide counseling, emergency services, shelter, medical care, support groups, social events, and other services to young people who are lesbian, gay, bisexual, or who are exploring their sexual orientation.

Organizations/Newsletters

The organizations and resources listed below can assist a support group.

AIDS Daily Summaries are summaries of articles about HIV in key newspapers and journal. These are posted each business day on the Centers for Disease Control's National AIDS Clearinghouse BBS and downloaded by HIV/AIDS BBSs around the country. Current and back issues are posted on CAM BBS (212-222-2135) in the DAILY (current) and AIDSNEWS (archive) libraries.

AIDS National Interfaith Network (ANIN)

300 I Street, NW, Suite 400
Washington, DC 20002
(202) 546-0807

Members of ANIN "believe that God reaches out to all who are affected by disease. We work to assure that everyone affected by AIDS receives compassionate respect, care, and assistance. We oppose threats to civil liberties, violations of confidentiality and all forms of prejudice and discrimination which contribute to the social epidemic surrounding AIDS. We educate people to respond to AIDS humanely and effectively. We call on everyone to address the AIDS crisis and the economic, racial, and sexual inequities which contribute to it."

AIDS Memorial Quilt

The NAMES Project
2362 Market Street
San Francisco, CA 94114-9926
(415) 863-5511

Making a quilt panel and visiting the quilt or portions of it are ways individuals and groups can work through their grieving process. Contact the project for information about the size of a quilt panel and other requirements and for showings of the quilt.

AIDS Treatment News, published twice a month by John James, reports on experimental and standard treatments. The staff interview physicians, scientists, other health professionals, and persons with AIDS or HIV; they also collect information from meetings and conferences, medical journals, and computer databases. The newsletter is available free in an online edition in the UPDATE library of CAM BBS (212-222-2135). For subscription information: Call 800-TREAT-1-2 or 415-255-0588.

Body Positive
2095 Broadway
Suite 306
New York, NY 10023
Contribution: \$35.00 a year

Body Positive Magazine is published monthly by Body Positive, an organization of and for people who are HIV positive. The newsletter contains a variety of articles, news, interviews, personal stories, poems, information about support groups, and treatment information written mostly by persons who are HIV positive. Some people may find some of the language offensive.

The magazine also has a free shorter "online version" that can be downloaded from the NEWSLET library of CAM BBS (212-222-2135) and other HIV BBSs.

Centers for Disease Control National AIDS Hotline
1-800-342-2437 (English)
1-800-344-7432 (Spanish)
1-800-243-7889 (Hearing-impaired and deaf)

Contact this hotline for AIDS information, particularly factual, statistical, resources, and prevention information.

Focus
UCSF AIDS Health Project
Box 0884
San Francisco, CA 94143-0884

Focus: A Guide to AIDS Research and Counseling is a monthly publication of the AIDS Health Project, affiliated with the University of California, San Francisco. Twelve issues of *Focus* are \$36 for U.S. residents, \$24 for those with limited incomes, \$90 for U.S. institutions. Make checks payable to UC Regents.

Kairos House
114 Douglass Street
San Francisco, CA 94114
415-861-0877

Kairos News is published quarterly to provide information, inspiration, recognition and support to those who care for persons affected by HIV and other life-threatening illnesses; and to maintain contact with contributors and supporters of KAIROS Support for Caregivers. To receive *Kairos News*, call 415-861-0877. *Kairos News* also has an "online edition" and may be downloaded from the NEWSLET library of CAM BBS (212-222-2135).

Kairos House is a non-profit service, offering non-judgmental, confidential help to parents, friends and lovers of AIDS-affected persons, as well as support to medical, nursing and other professional caregivers.

NAPWA

1413 K Street, NW
Washington DC 20005
Phone: 202-898-0414
(FAX) 202-898-0435

Medical Alert is published by NAPWA--the National Association of People with AIDS six times a year. It is a treatment-oriented magazine. *Medical Alert* has a free online edition that can be downloaded from the UPDATE library of CAM BBS (212-222-2135).

National AIDS Information Clearinghouse

P.O. Box 6003
Rockville, MD 20850
1-800-458-5231

The clearinghouse has or can refer you to printed and audiovisual resources in a variety of languages.

Treatment Update is a newsletter focusing on HIV treatment published by Gay Men's Health Crisis (GMHC). *Treatment Update* has a free online edition that can be downloaded from the UPDATE library of CAM BBS (212-222-2135).

AIDS-Related Electronic Bulletin Boards (BBSs)

This material is excerpted from a document prepared by the CDC National AIDS Clearinghouse. Inclusion of a service does not imply endorsement by the Centers for Disease Control and Prevention, the CDC Clearinghouse, or any other organization. Electronic bulletin board systems, often called BBSs or bulletin boards, are computerized information services that are accessed by using a computer, modem, and telephone line. Unless otherwise stated, services are free. The phone number listed can be dialed with a modem. AEGIS BBSs provide access to national and international forums. Messages posted on these forums are "echoed" on networks linking BBSs throughout the country.

CAM--Computerized AIDS Ministries.....**New York City, (212-222-2135, 2 lines)**

CAM is a free BBS for persons concerned about HIV information and support sponsored by Health and Welfare Ministries, General Board of Global Ministries, The United Methodist Church. It has public forums where people can converse with others on HIV-related concerns, private electronic mail (E-mail) and a library of files. (See references to some of these files in the annotated bibliography for Focus Paper 24.) CAM has two numbers 212-222-2135 and 800-542-5921. Those who can afford to do so are encouraged to call the 212 number. The 800 number has only one line and is often busy. Users are limited to 10-30 minutes a day. There is a waiting period before new users have full access.

CDC NAC ONLINE.....

CDC NAC ONLINE is the computerized information network of the CDC National AIDS Clearinghouse and gives non-profit AIDS-related organizations direct computerized access to the CDC Clearinghouse and its information and bulletin board services. It contains the latest news and announcements about many critical AIDS- and HIV-related issues. The system also features electronic mail and interactive bulletin board forums, and is the original source of the *AIDS Daily Summary* newsclipping service. CDC NAC ONLINE is a free service and can be accessed by dialing a toll-free number. Users must first obtain a username and password. For a registration form or more information, call the CDC Clearinghouse at (800) 458-5231.

AIDS Info BBS**San Francisco, CA; (415) 626-1246**

AIDS Info BBS is a long-established comprehensive electronic bulletin board targeted primarily to HIV-positive individuals, persons with AIDS, and others concerned about HIV infection. It contains hundreds of articles including *AIDS Treatment News*, electronic mail, and an open forum. Anyone can access AIDS Info BBS free. For more information, contact Ben Gardiner, AIDS Info BBS, P.O. Box 1528, San Francisco, CA 94101.

Black Bag BBS**Collegeville, PA; (610) 454-7396****(Internet address: ed@blackbag.com)**

Black Bag BBS, a member of the AEGIS network, is an electronic bulletin board containing information about many medical topics including HIV/AIDS. The Black Bag Medical BBS List is a comprehensive list of medical-related electronic bulletin boards in the United States and abroad. Black Bag BBS also includes *AIDS Treatment News*, AIDS statistics, and the FidoNet echo of the AIDS National Discussion. Donations are encouraged, but anyone can access Black Bag BBS free of charge. For more information, contact Edward Del Grosso, MD, P.O. Box 632, Collegeville, PA 19426.

HIV/AIDS Information BBS
San Juan Capistrano, CA; (714) 248-2836
(Internet address: mary.elizabeth@aegis.hivnet.org.)

HIV/AIDS Information BBS is the hub of the AIDS Education and General Information System (AEGIS), a growing network of HIV-related electronic bulletin boards. It includes many newsletters and hundreds of files that can be downloaded. It also echoes other networks including FidoNet and the international HIV-NET conferences. Anyone can access HIV/AIDS Information BBS free at connections up to 9600 baud. For more information, contact Sister Mary Elizabeth, Sisters of St. Elizabeth of Hungary, P.O. Box 184, San Juan Capistrano, CA 92693-0184.

HNS HIV-NET
Tollfree; (800) 788-4118

HNS HIV-NET is an electronic bulletin board for physicians and other health-care professionals treating HIV-positive patients and those with AIDS. It contains hundreds of files of newsletter articles, bibliographies, and graphics files of pictures of opportunistic infections. There are also a number of different forums, corresponding to different health-care professions. Interested users should dial the data line to register. After being validated or registered by the sysop (or "systems operator"), they can call back. For more information, contact John Owens, MD, HNS HIV-NET BBS, 9037 Kirby Drive, Houston, TX 77054.

NAPWA-Link
Washington, DC; (703) 998-3144

NAPWA-Link is the electronic bulletin board of the National Association of People With AIDS. NAPWA-Link contains electronic mail, announcements, and databases of news articles, drug interactions, and organizations. Anyone can connect for online information about NAPWA, NAPWA-Link, and HIV/AIDS, by logging on as a visitor. For more information, contact the National Association of People with AIDS, P.O. Box 34056, Washington, DC 20043, (202) 898-0414.

Positively Healthy
Portland, OR; (503) 243-2557

Positively Healthy is a community BBS, by, for and about people living with HIV. The focus of the board is becoming and remaining healthy while living with HIV. There are message areas for sharing experiences and downloadable files about treatment, alternative therapies, nutrition, and news.

Positively Aware



CD4 cells



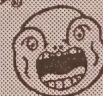
neutrophils

lymphadenopathy

T-cells

cytomegalovirus

macrophages



ganciclovir

eosinophils & basophils

coccidioidomycosis

asymptomatic

B lymphocytes



pathogenesis

Coming
to
TERMS

★
Cracking
the Language of HIV

From the editor

Issues of *Positively Aware* that focus on the basics of HIV and AIDS have proven to be the most popular we've ever done. In fact, requests for additional copies are still coming in. I hope that any of our readers who may feel that they have read it all already will be pleased to discover that here we present not only some widely familiar facts and figures but also up-to-the-minute information on treatments and life-style choices.

Anyone who lives or works with HIV knows that nearly everything involved with it can be time-sensitive—hardly a day goes by without some new insight in basic science or the exploration of some new treatment. The last year in particular has seen very large steps in the understanding of HIV pathogenesis and progression. For example, the illustrated explanation of HIV pathogenesis on pages 6–7 makes every effort to present a clear visual explanation of that process, but readers should understand that this is one of the most rapidly developing aspects of the science of HIV.

We feel that this issue of *Positively Aware* is unique in its effort to present a comprehensive, authoritative overview of HIV, while catching

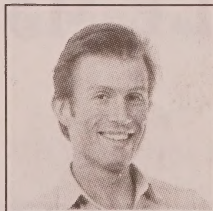
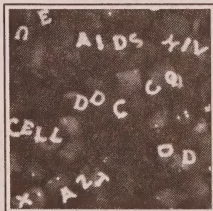
readers with entertaining graphics. On every page, however, we have kept sight of the human faces that always stand right beside every scientific advance or economic decision. Please share the knowledge and insights—or even the issue itself—with anyone you know who is in any way affected by HIV. For those who want to remain as up-to-date as possible, we have included a wide-ranging list of other HIV-related publications and how you can get them. We encourage you to cast your information-gathering nets as broadly as possible. ▲

CREDITS

Content review: Dr. Constance Benson, associate professor of medicine, Rush Medical College, and medical director of HIV inpatient unit; Dr. Andrew Pavlatos, family practitioner, St. Joseph Hospital, and board member of TPA; Dr. Ross Slotten, family practitioner; Lisa Williams, R.N., M.S., clinical nurse specialist, Northwestern Memorial Hospital. **Design:** Lisa Grayson. **Photography:** Genyphyr Novak. **Cover illustration:** Eric Orner, from his comic "The Mostly Unfabulous Social Life of Ethan Green." **Editorial coordination:** Scott Williams, former *Positively Aware* staff member. Sidebars, marginal notes, and captions were prepared by staff members and free-lancers John Servilio and Scott Williams.

THIS ISSUE

Inside



Myth-busting: facts about HIV	3
Immune-system basics	4
How HIV helps cause AIDS	6
Contents, pages 9–22	8
Early warning signs	9
Bacterial infections	10
Viral infections	12
Fungal infections	14
Pneumonias	16
Protozoal infections	18
Neurological manifestations	19
Malignancies (cancers)	20
Skin manifestations	22
Weight disorders	22
Potential drug interactions	23
Safer sex: what is it?	24
Commonly used HIV terms	25
Alphabet soup: anti-HIV drugs	26
News briefs	28
Referencias en español	30
Recommended reading	31
No matter what you call it... ..	32

POSITIVELY

Aware

Published monthly by Test Positive Aware Network, Incorporated
1340 West Irving Park, Box #259, Chicago, Illinois 60613
312-472-6397 (472-NEWS). FAX: 312-472-7505
Distributed in cooperation with HIV/AIDS service agencies

Editor: Steve McGuire

Assistant Editor: David Thomas

Staff Writer: Timothy Frick

Distribution Coordinator: Jeff Berry

TPA Executive Director: Steve Wakefield

Press run: 195,000. Contents ©Copyright 1993, Test Positive Aware Network, Inc. TPA Network is an Illinois not-for-profit corporation which provides information and support for anyone who is concerned with HIV and AIDS issues. For reprint permission or a copy of the monthly issue of *Positively Aware*, contact Jeff Berry. Non-commercial photoduplication and distribution of articles in this journal, with credit, is encouraged.

We reserve the right to edit or decline submitted articles. When published, the articles become the property of TPA Network and its assigns.

Publication and distribution
of the national edition of
Positively Aware is made possible
through a grant from
Burroughs Wellcome Co.

Myth-busting: facts about HIV

By David Thomas

More people have heard about HIV and AIDS in 1994 than ever before. There's no doubt that the epidemic has come a long way: While former President Reagan took seven years to even say the word "AIDS," the U.S. Postal Service has now issued a stamp of the red ribbon that has long symbolized AIDS awareness.

But what do people really know about the epidemic? Misconceptions abound about how a person can become infected, who can become infected, and how the virus causes disease.

This issue of *Positively Aware* tries to clarify some of those misconceptions.

HIV vs. AIDS

HIV stands for "human immunodeficiency virus." More precisely, HIV is a retrovirus, a kind of viral organism that also includes the agent that causes some types of leukemia. No one knows for sure where HIV came from or how long it's been around. Some theories say it is a new retrovirus, mutated from some non-harmful strain; others think it has existed for decades, perhaps centuries, and has only recently become a public health threat.

Infection with HIV can lead to development of AIDS—Acquired Immunodeficiency Syndrome. *Acquired* means the illness is not inherited from a parent. *Immunodeficiency* describes the condition: a defect (deficiency) in the body's method of protecting itself (the immune system). *Syndrome* means that AIDS cannot be defined by a single disease or illness but by a collection of them.

HIV and AIDS are not interchangeable terms, although the media often use them that way. HIV is an organism. AIDS is a disease. In fact, a person can have HIV for many years without showing any symptoms of or being diagnosed with AIDS. The only way you can know whether you have HIV is to take the HIV-antibody test. If you test positive for antibodies and show no symptoms, you are said to have "asymptomatic HIV disease." Some people have been infected with HIV for more than 15 years and have no symptoms.

When an HIV-positive person develops minor symptoms, it may be a sign that disease is progressing. When this happens, it is important for a physician to monitor your health more closely—including getting more regular CD4 cell counts. See page 9 for more details about these early warning signs. To learn what illnesses or conditions bring about an actual AIDS diagnosis, see page 8. We have also marked these conditions with an asterisk (*) on pages 10–22.

Risk groups vs. risk behaviors

There is no such thing as a high-risk group. Everyone is eligible for HIV infection. Unlike many people, the virus does not discriminate based on sex, religion, race, ethnicity, sexual orientation, national origin, or economic class. A gay white male's immune system is just as susceptible as a married black woman's.

High-risk behaviors, however, are a reality. A high-risk behavior is anything that has the potential to allow HIV-infected blood, blood products, semen, breast milk, or vaginal secretions to come into contact with blood, such as through an open wound or syringe prick, or with mucous membranes, especially the tender anal and vaginal tissues during sex. See page 24 for more information about no-, low-, medium-, and high-risk behaviors and how to protect yourself and others from HIV infection.

As of January 1994, more than 340,000 people in the United States have been diagnosed with AIDS, and as many as 1.5 million are infected with HIV. The World Health Organization estimates that more than 14 million people worldwide have HIV. One million of these are children. The U.S. Public Health Service estimates that AIDS was the eighth leading cause of death in the United States in 1993. It is the leading cause of death among young American men ages 25–44. AIDS is the leading cause of death among young women in the same age group in four U.S. cities.

To illustrate the point that no one is immune to HIV, photos throughout this issue feature some real people affected by HIV and information about the epidemic in their communities. Please share this message with friends and family in your own community. ▲

▼
▼
▼

Young African-Americans are disproportionately represented among people with HIV. While African-Americans constitute about 14 percent of the American population, they represent 31 percent of all U.S. AIDS cases. AIDS is the leading cause of death for young black men age 15–24. More than half of all women with AIDS are black. African-American-led AIDS service organizations are creating culturally sensitive outreach campaigns to fight the epidemic.



Immune-system basics

By David Thomas

Illustrations by Jennifer Bennett

Warfare seems simple: Whoever's got the biggest army wins. But as many a surprised general has learned, war's a lot more complicated than that. Technology, maneuverability, strategy, and battlefield communication all play important roles.

Human biology learned this lesson faster than human behavior. The immune system—our personal, internal army—uses an enormous variety of techniques to attack and defeat pathogens, a blanket term for invading organisms such as viruses and bacteria.

Therefore, explaining the immune system is about as easy as explaining a nuclear reactor. But understanding how your immune system works and how HIV causes AIDS can be an important step in taking control of your health.

After reading this very simplified explanation of the human immune system, turn the page to learn how it specifically relates to its battle against HIV.

Technology

The biggest strength of the immune system lies in its vast arsenal of specialized warriors, called white blood cells. Among the different groupings of white blood cells are lymphocytes and granulocytes, both of which have many subsets of their own.

T-lymphocytes (T-cells). Most people with HIV talk about their "T-cells," as in, "My boss's nagging cost me 20 T-cells today." The cells in question are actually CD4 T-cells, which are the primary target of HIV infection. The "T" stands for "thymus," a gland in the chest that plays an important role in immunological development.

T-cells come in many forms. What distinguishes them—and their immune functions—are proteins embedded on their surface. The proteins CD4 and CD8 are the two most important for this discussion. If a T-cell has a CD4 protein, it is called a CD4+ T-lymphocyte, or just a CD4 cell. (The "+" is pronounced "positive" and simply means the protein is present.)

CD4 cells have many roles in fighting infections, which is why their destruction by HIV causes so much upheaval in the immune system. They are like army generals, coordinating different types of white blood cells in their respective battles.

CD8 cells are the real trench fighters of the immune system. They are often referred to as cytotoxic T-lymphocytes (CTLs) or killer T-cells. CD8 cells directly attack pathogens as well as rid the body of its own infected cells.

B-lymphocytes. B-lymphocytes, also called B-cells, get their name from the "bursa," a gland in birds, where this kind of cell was originally discovered.

The most important role of B-cells is to create antibodies, proteins that neutralize pathogens.

Macrophages. These white blood cells, also called monocytes, ingest pathogens directly. Like "The Blob," they reach out with tentacles, surround their prey, and absorb it. Some macrophages carry a CD4 protein and can be infected, disrupted, or killed by HIV. But the virus cannot replicate within a macrophage.

Neutrophils. Neutrophils are powerful warriors against bacterial infections. HIV infection specifically can cause neutropenia, or a shortage of neutrophils, which makes a person very susceptible to bacterial infections ("penia" is a suffix meaning "shortage of").

Eosinophils and basophils. These kinds of white blood cells are involved in allergies. They are not particularly affected by HIV infection.

Glad wrapped

Those of you who enjoy performing oral sex on a woman but can't seem to find those elusive dental dams, run to the supermarket and buy some plastic wrap. It's an effective barrier against HIV, and some people like it better because you can buy it by the yard rather than three-inch squares. Also, no nasty latex taste!

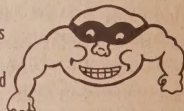
T Lymphocytes:



Long-lived cells
responsible for
cell-mediated
immunity

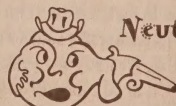
CD4s: Use cytokines to orchestrate the battle

CD8s: Killer cells
that directly attack
foreign bodies or infected
cells



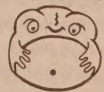
Neutrophils:

Fight bacterial infections



Macrophages:

Ingest bacteria, invaders, or other cells

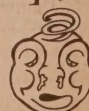


B Lymphocytes:

Short-lived cells that make antibodies

Eosinophils & Basophils:

Involved in allergies



Maneuverability

Blood may seem to be the most likely immune-system battlefield. But the lymph nodes are where the biggest wars are fought. Like an army maneuvers its enemy into a box canyon, the body herds pathogens through the lymph nodes, which are rich in white blood cells that overwhelm pathogens as they pass through.

Mucus membranes—a weak point in the skin—are also rich in immune cells. Since mucous membranes are slightly porous, like a sponge, viruses and some other pathogens are able to pass through. With immune cells ready and waiting at the surface of these membranes, pathogens may be stopped before infection can be established. Mucous membranes are parts of the skin that need to be kept moist, such as the lips, mouth, vagina, and tip of the penis. Sex is an important route of transmission for pathogens because the sex organs are mucous membranes. When a person already has a sexually transmitted disease, sex organs may be flooded with CD4 cells—making it that much easier for HIV to infect.

Strategy

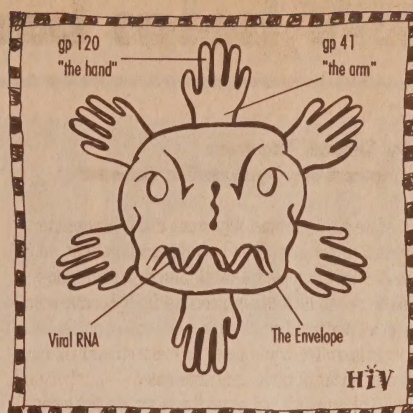
The immune system has two attack strategies. One, called “cell-mediated” immunity (CMI), uses T-cells for rapid, initial protection and to clear the body of infected cells. The other, called “antibody” (or “humoral”) immunity, uses B-cells to produce antibodies that can prevent cells from becoming infected in the first place. One role of antibodies is to attach like neon signs to pathogens, marking them for destruction by macrophages or other immune cells.

The two strategies may be somewhat exclusive of each other. The stronger the CMI, the weaker the antibody immunity, and vice-versa. A growing body of evidence shows that the CMI response is much more effective against HIV infection than antibodies. This may cause a problem as infection intensifies, antibody production is stepped up, and the CMI grows weaker.

Communication

All these players and battle plans are efficiently orchestrated by chemical messengers called cytokines. Different kinds of white blood cells secrete different cytokines, although CD4 cells play a leadership role. Some cytokines step up CMI, some step up antibody production, and others stimulate or repress growth of certain kinds of white blood cells. HIV infection can disrupt the natural pattern of cytokines, wreaking havoc indirectly on the immune system.

This is an exaggerated, simplified account of how parts of the immune system work—which no one understands perfectly anyway. But what should be apparent from this discussion is that more “basic” research into how immunity works must be conducted before science can conquer HIV infection once and for all. ▲



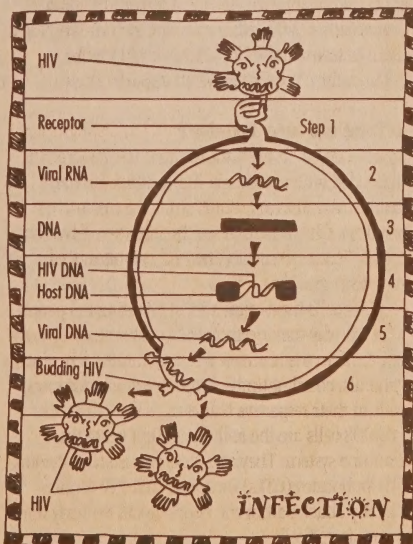
HIV anatomy

The most important parts of HIV's anatomy are its envelope, envelope proteins, and genetic material, called viral RNA. You may recognize the envelope protein gp120 by name—it is an important player in vaccine research. Together, gp120 and gp41 are known as gp160, also familiar to those following vaccine research.



How HIV binds to a CD4 cell

The reason HIV infects CD4 cells—rather than, say, liver cells—is because the gp120 protein on HIV's envelope is a “mirror image” of the CD4 protein on CD4 T-lymphocytes. They fit to each other like puzzle pieces, stick together, and give HIV an opportunity to invade the host CD4 cell.



Countdown to reproduction

Here is a simplified explanation of how HIV uses a CD4 cell to reproduce.

1. gp120 binds to CD4.
2. HIV melts into the cell wall and releases its viral RNA.
3. Viral RNA produces DNA (this is the process that AZT, ddI, and ddC try to interrupt).
4. Cell DNA is broken and viral DNA is inserted.
5. Cell begins to reproduce: DNA is activated; viral RNA copies are formed in the process.
6. Viral copies “bud out” of the cell to infect new cells.

How HIV helps cause AIDS

By David Thomas
Illustrations by Jennifer Bennett

HIV, through evolutionary chance, has hit upon infecting the part of the body designed to fight invasion of any kind—the immune system. The nature of HIV infection leaves the body open to more virulent attacks by HIV as well as from opportunistic organisms that could never have the strength to cause harm under normal circumstances.

The previous two pages discussed the immune system and the process by which HIV infects a cell and converts it to a factory for replication. But how does HIV infection help cause AIDS?

Condom sense

Not all condoms are created equal. Although the FDA requires that no more than four out of every 1,000 of a manufacturer's condoms fail, some private organizations have conducted their own tests and have ranked condoms according to reliability. Surprisingly, some of the best-known brand names don't even make it to the top ranks. One set of tests was run by the California-based Mariposa Foundation. A copy of their report of the test results is available by sending \$2 to Mariposa Foundation, 3123 Schweitzer Dr., Topanga, CA 90290.

The great unknown

Medical scientists don't have an exact answer to that question. But the past year and a half has seen huge strides forward in the understanding of the pathogenesis of HIV disease. And the more light researchers shed on pathogenesis, the better equipped they are to find ways to defeat it.

One big unknown is whether HIV acts alone in causing AIDS. Scientists have proven conclusively now that HIV plays the pivotal role and can probably cause AIDS all by itself. But there may be other organisms that speed the process along or increase the likelihood that AIDS will eventually develop. When a person develops an AIDS-like condition but tests negative for HIV—which is extremely rare—the condition is called "Idiopathic CD4 T-lymphocytopenia" and is classified as a different disease with similar symptoms, like a tension headache and a sinus headache. ("Idiopathic" means "cause unknown.")

What do we know?

So what do we know? We know that HIV disease has many different aspects and many different phases. Unlike most illnesses, which strike the majority of people in the same way with the same symptoms in the same time frame, HIV disease can affect people in very different ways.

Studies indicate that almost 20 percent of people with HIV show no symptoms after more than 10 years of infection, while others progress to AIDS very quickly.

This period of health between primary infection and an AIDS diagnosis is known as the "clinically latent" period and usually lasts eight to 10 years. Scientists used to think the virus was inactive during this time but recently discovered that HIV is quite actively replicating in the lymph nodes throughout infection—the body just doesn't show any outward

signs of it. The same evidence strongly discredits many theories that HIV isn't the cause of AIDS.

We know that HIV comes in many different strains, some of which are fairly weak and some of which are very powerful. One person can harbor scores of different strains. People seem to become infected with weak strains, which independently mutate into strong ones. The switch can lead to the development of AIDS.

HIV is able to destroy the immune system directly, by killing cells, and indirectly, by causing malfunctions that prompt cells to kill themselves.

The facing page offers a visual guide to the steps of a typical HIV disease progression. You will understand it more easily if you've read pages 4–5 first.

HEALTH WATCH CD4 cell counts

A fact of life with HIV is monitoring CD4 cell count. Although the relationship between the number of CD4 cells a person has and his or her relative state of health is a matter of some controversy, most healthcare professionals agree that CD4 count is the best predictor of health currently available.

A normal CD4 count is 800–1200 cells per cubic millimeter of blood. A person is not "immunocompromised" until his or her count falls below 500. When count falls below 250, signs of disease progression may begin to occur, and when CD4 count drops under 200, a person is at much greater risk of opportunistic infections. A consistent CD4 count below 200 now constitutes a definition of AIDS.

People with HIV should have their CD4 count monitored at least every six months, or more often for those on medication or when CD4 count falls below 250. CD4 counts rise and fall daily and hourly, so for each blood test, blood should be drawn at about the same time of day and should be tested by the same lab.

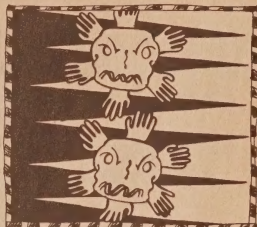
Keep track of your CD4 counts and monitor the trends. A slow, steady decline is common to almost all people with HIV infection, although anti-HIV drugs like AZT and ddI may cause the count to rise, sometimes dramatically, for as long as two years.

A rapid decrease in CD4 cells is a sign that disease is progressing. Inform your physician and ask about ways to protect against opportunistic infections. Most physicians will recommend antiretroviral therapy.

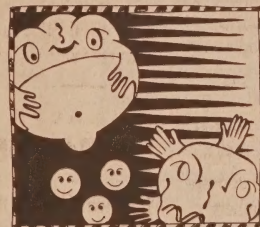
Other markers of disease progression are CD4 percentage, CD4/CD8 ratio, and levels of proteins such as p24 antigen, beta-2 microglobulin, and neopterin.

[FPO hed: HIV disease progression, illustrated]

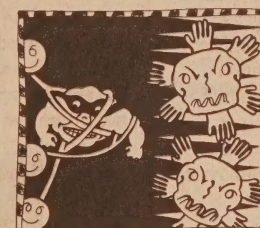
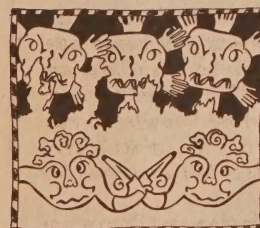
HIV disease is characterized by many phases and many factors, which may take different courses in different people. This page illustrates a typical course of disease progression. Some of these steps may happen quickly in some people while taking much longer in others. Some people may not experience some of the steps at all.



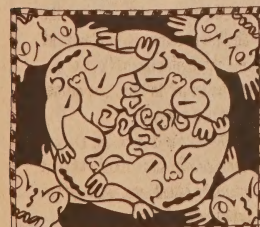
Primary infection. 1. HIV enters body, attacks CD4 cells. 2. Virus replicates rapidly, CD4 count drops, flu-like symptoms develop. 3. Immune system fights back: CD4s stimulate CD8 cells to mount assault against the virus, called cell-mediated immunity (CMI). 4. HIV becomes trapped in the lymph nodes.



Two weeks to two months later. 5. "Clinical" latency begins (no symptoms can be seen), CD4 count rises, CD8s maintain strong resistance to HIV. 6. B-cells begin producing antibodies; infected person now tests HIV-positive. 7. Between cell-mediated, antibody, and lymph response, amount of virus in the blood drops to almost nothing. 8. In the lymph nodes, however, virus continues to replicate. CD4 cell count slowly declines over the next several years.



During the next few years.... 9. HIV disrupts the immune system's communication system, called the cytokine network. The malfunction may indirectly kill CD4 cells by sending them a signal to prematurely destroy themselves. 10. As the antibody response grows stronger, it weakens the CMI—which some consider to be more effective against HIV. Virus gains the upper hand. 11. CD4s lose stimulating effect on CD8 cells, further weakening the CMI. HIV gains more strength. 12. HIV begins its escape from the lymph nodes, increasing the number of infected cells circulating in the blood. The virus also attacks macrophages, gut, and brain cells.



Late-stage disease, eight to 10 years after infection. 13. Rapid viral replication may lead HIV to mutate into a much more powerful strain, called a syncytium-inducing (SI) strain because it can kill uninfected CD4s by dissolving their cell membranes and causing them to clump together into a "syncytium." CD4 count plummets abruptly. 14. Early warning signs of disease progression develop (see page 9). 15. Lymph nodes collapse, and the immune system loses the ability to regenerate itself. 16. Advanced HIV disease or AIDS develops; opportunistic infections occur.

Contents, pages 9-22

While a variety of illnesses may accompany HIV infection, AIDS itself is defined by the occurrence of a number of opportunistic infections—caused by organisms such as bacteria, viruses, protozoa, or fungi—or conditions—malignancies, wasting, dementia. We have divided this section on AIDS-defining conditions and other disorders into these categories. Listed below are the names and page numbers of specific illnesses, symptoms, or conditions contained in this section. (Asterisks [*] indicate AIDS-defining conditions.)

Ano-genital warts	13	Herpes Simplex virus*	12	Pneumonia (bacterial)*	17
Aphthous ulcers		Histoplasmosis*	15	Pneumonias	16
(canker sores)	21	Invasive cervical cancer*	20	Progressive multifocal	
Aspergillosis	15	Isosporiasis*	18	leukoencephalopathy (PML)*	19
Bacterial infections	10	Kaposi's sarcoma	20	Protozoal infections	18
Candidiasis*	14	Lymphoid interstitial		Psoriasis	22
Coccidioidomycosis*	15	pneumonia (LIP)*	16	Salmonellosis*	11
Cough	9	Lymphoma*	20	Seborrheic dermatitis	22
Cryptococcal meningitis*	14	Malignancies (cancers)	20	Skin manifestations	22
Cryptosporidiosis*	18	Molluscum contagiosum	13	Skin rash	9
Cytomegalovirus (CMV)*	12	<i>Mycobacterium avium</i>		Swollen glands	9
Dementia*	19	complex (MAC)*	10	Toxoplasmosis*	18
Diarrhea	9	<i>Mycobacterium genovense</i>	11	Tuberculosis*	11
Encephalitis	19	Neurological manifestations	19	Varicella-Zoster virus*	12
Epstein-Barr virus (EBV)	13	Neuropathy	19	Viral infections	12
Fatigue	9	Night sweats	9	Wasting syndrome*	22
Folliculitis	22	Non-Hodgkin's lymphoma*	21	Weight disorders	22
Fungal infections	14	Oral problems	9	Weight loss	9
Gingivitis	21	Oral hairy leukoplakia	21		
Hepatitis	13	Periodontitis	21		
		Persistent fever	9		
		<i>Pneumocystis carinii</i>			
		pneumonia (PCP)*	16		

Sidebars

Defensive eating	11
Women & HIV	13
Preventive medicine	15
Clinical trials	17
Oral health	21

Gina found out she is HIV-positive two days before learning she was pregnant with her son, Juan David. Research conducted around the world on mother-to-child transmission of HIV puts the risk at 14 percent to 30 percent, and Juan David is one of the majority of kids born without the virus. About 1.5 percent of the epidemic is among children born to infected mothers, while another 4.5 percent of the epidemic is among youth under 24, regardless of manner of infection. Public health advocates are pressing for more direct, less homophobic HIV prevention and education efforts among youth before a youth HIV explosion occurs.



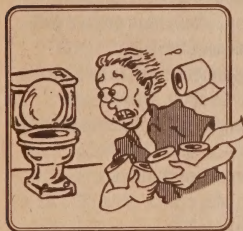
Early warning signs

Many of the symptoms below are common to a variety of illnesses. However, persistence of any of them for several weeks, especially in the absence of any other potential cause, could signal progression of HIV disease.

Entering a new phase of HIV disease can have several implications. Among them may be the need to get more frequent CD4 cell

counts and other blood chemistry work-ups or beginning prophylactic (preventive) medication that could delay or avoid the onset of certain opportunistic infections. See the sidebar on page 15 for more information about prophylaxis.

If you experience any of these potential warning signs, consult your doctor for treatment and seek information immediately. ▲



diarrhea

Runny bowel movements several times daily that occur repeatedly for many weeks.



cough

A dry cough lasting several days or longer, in the absence of an illness such as a cold.



fatigue

Chronic tiredness during regular daily activities, despite plenty of sleep.



persistent fever

Prolonged temperature of 99–101 degrees in the absence of an illness such as the flu.



swollen glands

Enlarged lymph glands in the neck, groin, or armpit. May be sore or tender.



night sweats

Sweats that soak the bed sheets, with or without a fever.



skin rash

Itchy bumps or ulcers appearing anywhere on the body; they often spread. See page 22.



weight loss

Loss of 10 pounds or more without dieting or change in regular intake of food. See page 22.



oral problems

Sores or white patches (thrush) on the gums, tongue, or palate. See candidiasis, page 14.

Illustrations developed by Chicago cartoonist Tim Jackson from his series of HIV/AIDS education material. For information, call Creative License Studio, 312-338-5809.

Bacterial infections

Bacterial infections are health problems caused by bacteria—single-cell organisms that lack any nucleus. These tiny organisms may cause illness in the gastrointestinal tract (diarrhea, abdominal pain), the lungs (pneumonia), the heart (endocarditis), the brain and spinal cord (meningitis), the urinary tract, the sinuses, and almost any other body organ.

Other serious bacterial infections include salmonella, syphilis, and sepsis—a dangerous blood infection.

Mycobacteria are a type of bacteria that cause a variety of serious infections in persons with HIV. Tuberculosis (TB) is caused by *Mycobacterium tuberculosis*.

Mycobacterium avium complex (MAC) and even rarer forms of mycobacteria (*M. bovis*, *M. kansasii*, *M. marinum*) ordinarily cause local infections of skin and lymph nodes, or cause lung infections in persons with pre-existing lung disease. HIV infection allows these organisms to spread to other areas of the body.

A mycoplasma is another kind of bacteria believed to be the smallest free-living organism in humans. Many strains cause a variety of illnesses. Infections of the lung or sexual organs are most common. *Mycoplasma incognitus* and *Mycoplasma penetrans* are suspected of contributing to the progression of HIV infection but have not been proven to do so.

Bacterial infections greatly reduce the immune system's ability to fight off other serious infections.

Get it right

News alert! People become infected with HIV, not the HIV virus—"virus" is what that V in the acronym stands for! And people are never "AIDS infected," which is like saying "diabetes infected." AIDS is a condition, not an organism that can infect you.

Mycobacterium avium Complex (MAC)*

Mycobacterium avium Complex (MAC) is the most common HIV-related disorder caused by mycobacteria (tuberculosis and leprosy also are caused by mycobacteria). MAC may be picked up from the water supply, but there is no definite way to avoid contamination. The organism may exist in the body without causing disease, but in persons with AIDS, infection throughout the body is common, with disease often beginning in the gut.

MAC most often affects people with fewer than 100 CD4 cells, and may be the first AIDS-defining illness because the incidence of PCP has diminished dramatically as a result of prophylaxis. Common symptoms of MAC include night sweats, fever, weight loss, and diarrhea.

Rifabutin is approved for the prevention (prophylaxis) of MAC in HIV-infected individuals with CD4 counts below 100. MAC prophylaxis should continue for a person's lifetime.

Several drugs used alone or in combination may reduce or eliminate bacteremia, the presence of living MAC in the blood. MAC is optimally treated with a combination of at least two drugs, often clarithromycin and clofazimine. Azithromycin, rifampin, rifabutin, ethambutol, clofazimine, and ciprofloxacin are other drugs shown to benefit persons with MAC. But patients must often discontinue treatment because of adverse reactions.

Tuberculosis*

Tuberculosis (TB) has become a serious health problem for HIV-infected persons. In some cities, forms of TB occur that resist treatment, even with multiple drugs. This type is called "multidrug-resistant TB" (MDR-TB).

Many people are first infected with TB early in life, but the infection remains dormant. Active TB is especially serious when the immune system is suppressed by HIV. TB may occur before other opportunistic infections appear, and this may be a tipoff to possible HIV infection.

Mycobacterium tuberculosis is the organism that causes TB. The disease is highly contagious—a TB-infected person can spread it through coughing or sneezing.

When TB affects the lungs, it is called pulmonary TB. When it involves other parts of the body, it is called *extrapulmonary* TB, which may affect the bones, gut, lymph nodes, and other parts of the body. Both forms of TB are AIDS-defining illnesses in the HIV-infected person. Symptoms of pulmonary TB may include fatigue, fever, night sweats, weight loss, and a cough that produces mucus and sometimes blood.

HIV-positive people should get a PPD skin test; a positive test indicates exposure to the TB organism.

PATIENT ASSISTANCE

Bacterial infections

Drug	Pharmaceutical company	Phone number
Azithromycin	Pfizer	800-742-3029
Ciprofloxacin (Cipro)	Miles	800-998-9180
Clarithromycin (Biaxin)	Abbott Laboratories	800-688-9118
Clofazimine (Lamprene)	Geigy	908-277-5000
Ethambutol (Myambutol)	Lederle Laboratories	800-533-2273
Pyrazinamide	Lederle Laboratories	800-533-2273
Rifabutin (Mycobutin)	Adria Laboratories	800-795-9759
Rifampin (Rifadin)	Marion Merrell Dow	816-966-4000

However, if the immune system is impaired, this test is not always accurate. Sometimes the test is negative despite prior exposure. Therefore, HIV-positive individuals with symptoms of TB also need a chest X-ray and sputum tests.

If only the PPD skin test is positive, the CDC recommends prophylaxis with isoniazid (INH) for 12 months. If sputum or blood samples are positive, or if a chest X-ray shows signs of TB infection, the CDC recommends that a multidrug treatment regimen be started immediately.

For active TB, INH and rifampin are used for nine to 12 months, with pyrazinamide and ethambutol (or streptomycin) also recommended during the first two months of therapy.

Patients *must* complete the full treatment regimen to ensure that TB does not occur.

Salmonellosis*

Salmonellosis, a common form of food poisoning, is caused by salmonella bacteria. Illness from salmonella is 20 times more common among HIV-positive people than among HIV-negative persons.

Salmonella is acquired by consuming contaminated water or food—particularly undercooked chicken or eggs. It is therefore important that HIV-positive individuals avoid homemade ice cream, fresh

caesar salad dressing, and eggnog, as they may contain salmonella. Traces of fecal matter are common sources of contamination; therefore salmonella may also be spread through oral-anal contact.

Symptoms of salmonellosis include nausea, abdominal cramps, fever, loss of appetite, and diarrhea that may be severe or bloody. The organism may affect any organ system. Infections occur repeatedly in individuals whose immune systems are impaired by HIV.

Diagnosis is usually made by culture of blood and stool samples. Although most people recover even without treatment, antibiotics should be used in HIV-positive patients with salmonellosis.

Mycobacterium genovense

This newly discovered organism can cause body-wide infection in persons with AIDS and very low CD4 counts and causes the same symptoms as MAC. It is not yet known how common the organism is. It seems to respond to the same therapies as used for MAC, although the most effective therapy is not known. ▲

Richard DeRath has had an AIDS diagnosis for five years, while current roommate and former lover Peter Merced is HIV-negative. Such "discordant" relationships are increasingly common in the gay community, which has learned through years of living with the reality of AIDS and safer sex that barriers between positive and negative exist as much in the mind as in the body. While AIDS has been, and to a lesser extent still is, associated with the gay community, the percentage of HIV-positive American men who are gay is decreasing. Gay men were 61 percent of AIDS cases reported in 1992; they were 48 percent in 1993.

NUTRITION

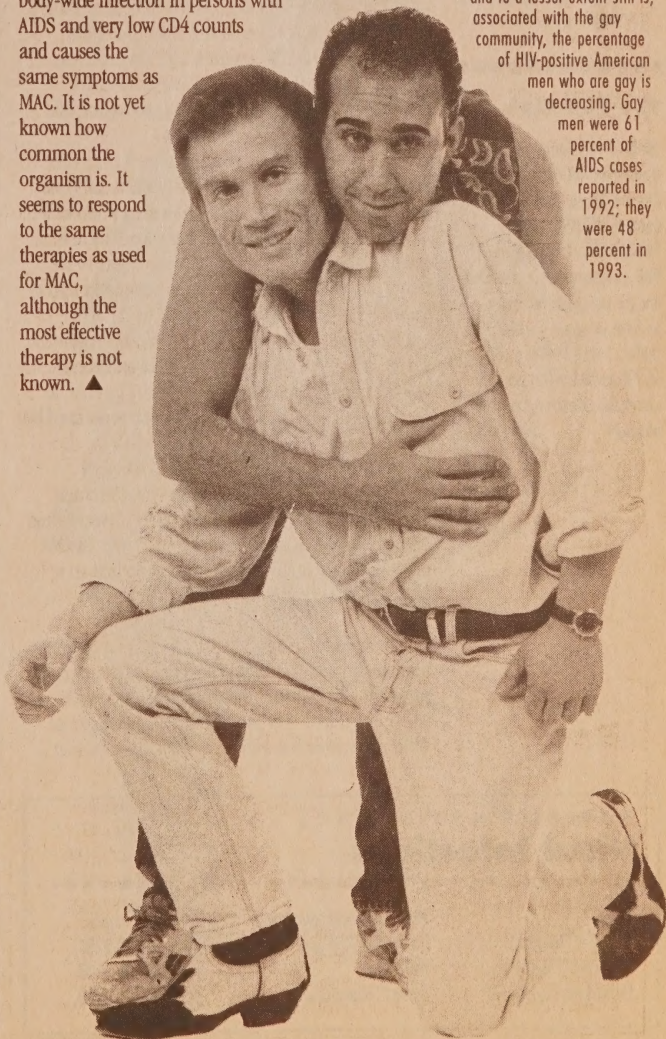
Defensive eating

Eating can be one of life's great sins, but eating raw or improperly prepared foods could be a mortal sin for people with very advanced HIV disease, who are at greater risk for food-borne illnesses. Among these illnesses are botulism and salmonellosis, which can cause severe diarrhea.

A food-safety strategy, or "defensive eating," can help reduce your chances of food poisoning. Some tips:

- Avoid potato, egg, chicken, or macaroni salads at supermarket delis.
- Buy only pasteurized milk and eggs in the shell.
- Don't chop raw vegetables with the same knives and cutting boards you've just used to cut raw meats.
- Avoid thawing frozen foods at room temperature. Instead, thaw them in the refrigerator, in the microwave, or under cold running water.
- Double wrap meats and store on low fridge shelves.
- Don't keep leftovers for more than three days.
- Avoid raw eggs, which are often used in home-made mayonnaise, eggnog, and in some fresh restaurant salad dressings.
- Ask for a fresh container of cream in restaurants that leave them on tables throughout the day.

Defensive eating is not paranoid eating. Food-borne illnesses account for a small fraction of AIDS-related illnesses. But prevention plays a part in that.



Viral infections

Viral infections are some of the most difficult for the body—and for drugs—to fight. Whereas most illnesses are caused simply by a foreign organism invading the body as a whole, a virus acts much more insidiously—it infects individual cells. Next, the virus disrupts natural cellular processes and converts the cell into a factory for virus production. Unlike other microorganisms, which are independent and self-perpetuating life forms, a virus cannot survive for long or reproduce at all without infecting a host cell.

Drugs can only arrest a viral infection, not remove all virus from the body. Therefore, while treatment may end symptoms and send a virus into a dormant state, the latent infection can be reactivated at some point in the future, requiring additional treatment.

Cytomegalovirus (CMV)*

CMV is a common virus related to the Herpes simplex virus. CMV usually remains inactive in healthy people. The virus lives in blood cells and often multiplies when the CD4 count is less than 100. The infection initially causes fever, fatigue, and weight loss and resembles mononucleosis. Often symptoms are mild or absent.

CMV is a systemic disease, meaning it can occur throughout the body. In persons with AIDS, CMV can infect the central nervous system. It can also infect the lungs, causing pneumonia. In the brain, CMV can cause encephalitis, a swelling of brain tissue. In the colon, it causes cramps and diarrhea. Hepatitis results from CMV infection in the liver.

Retinitis—inflammation of the retina—occurs in as many as a quarter of PWAs and is the most common form of CMV infection. Vision changes, such as spots, floaters, or tunnel vision, should be evaluated by an eye doctor.

CMV retinitis can be detected early through regular eye exams. If not treated early, it can cause blindness. Currently, a nationwide study is examining the benefits of oral ganciclovir for prevention of CMV retinitis. CMV retinitis is treated with ganciclovir or foscarnet and requires continuing maintenance therapy.

Preliminary research has suggested that combination therapy with ganciclovir and foscarnet may be a better initial treatment for CMV than therapy with either drug alone. For patients with gastrointestinal CMV, ganciclovir has a slightly greater benefit than

foscarnet. Also, ganciclovir implants and injections directly into the eye may be effective alternatives for persons with CMV retinitis who cannot tolerate intravenous ganciclovir therapy. But these techniques are still experimental and not performed routinely.

Herpes Simplex Virus*

Herpes simplex virus type one (HSV-1) and Herpes simplex virus type two (HSV-2) can occur in anyone, but they can be especially troublesome in HIV-infected people.

HSV-1 causes cold sores or blisters, usually on the mouth or the face; HSV-2 causes similar sores, most often in the genital or anal area. If the immune system is severely weakened, the Herpes virus can also cause ulcers elsewhere, including the esophagus and colon, or inflammation of the brain.

Herpes sores are usually small red bumps, or fluid-filled blisters that break and then crust over. The affected area may be itchy, swollen, and painful.

Herpes infections can be more severe in HIV-infected persons than in persons whose immune systems are functioning normally. Herpes sores may be larger; outbreaks may be more frequent and longer-lasting; and symptoms of fever, fatigue, or headache may be more acute.

Herpes lesions have a typical appearance but may be confirmed through a lab culture or biopsy. Herpes may be treated with the antiviral acyclovir in topical, oral, or intravenous form. Acyclovir may be prescribed for daily use to prevent frequent Herpes infections. Foscarnet is used in some forms of Herpes that are resistant to acyclovir.

Varicella-Zoster virus (shingles)*

Varicella-Zoster virus (VZV), a member of the Herpesvirus family, causes a condition commonly known as shingles. It most often appears among elderly or immune-suppressed people, including those with HIV.

Shingles is due to a reactivation of varicella-zoster, the virus that causes chicken pox. VZV causes small, very painful blisters that follow nerve pathways, usually along one side of the body.

The 900 Club

The first 900 number was created by ABC-TV during the Reagan/Carter presidential debates in 1980. Then in 1982, NASA started using a 900 number as an information line for people to get quick updates on space shuttle flights. In the 1990s, a surge of 900 numbers has become about the safest way to have hot sex!

PATIENT ASSISTANCE

Viral infections

Drug	Pharmaceutical company	Phone number
Acyclovir (Zovirax)	Burroughs Wellcome	800-722-9294
Foscarnet (Foscavir)	Astra USA	800-388-4148
Ganciclovir (Cytovene)	Syntex Laboratories	800-444-4200

Treatment with acyclovir within the first three days of an VZV outbreak is the most effective therapy. Valacyclovir, a new formulation of acyclovir not yet available commercially, requires fewer daily doses, may work more quickly, and is better absorbed by the body.

Hepatitis

Hepatitis is an inflammation or infection of the liver. The most familiar forms are caused by viruses and include hepatitis A, B, and C. Hepatitis may also be caused by CMV or Epstein-Barr virus, medications, or by alcohol or drug abuse. Symptoms include fever, abdominal pain, and jaundice—yellow discoloration of the skin and eyes.

Hepatitis A can be spread through unsanitary living conditions, sex, or contaminated food. Hepatitis B is usually spread through sexual contact, one more reason to practice safer sex. Tainted blood transfusions can also transmit hepatitis. A vaccine is available against hepatitis B.

Epstein-Barr virus (EBV)

EBV is a Herpes-like virus that causes mononucleosis—a disorder known for causing extreme fatigue. EBV is being investigated as a factor that may contribute to the progression of HIV disease. It may also be the cause of oral hairy leukoplakia. (See page 21.)

Ano-genital warts

Ano-genital warts are raised bumps or protruding pieces of skin in the anal or genital area. In HIV-positive people, they are most often caused by human papillomavirus (HPV) and can spread quickly on the body or from one person to another through sexual

contact. Treatment is difficult, but may include freezing, cautery, or use of podophyllon, an acid solution. Without treatment, the warts may spread and cause much discomfort and complications.

Molluscum contagiosum

This is a viral infection that causes small, white, wart-like bumps on the skin—especially on the face, but they may occur anywhere on the body. These may be removed by zapping them with an electrical charge or by freezing them with liquid nitrogen. Shaving may scrape the bumps, causing them to bleed; single use of disposable razors may slow their spread. The warts are painless; the major problem is cosmetic. ▲

▼
▼
▼

Lisa tested HIV-positive in January 1988—but she believes she's been infected since 1985, long before most people, including physicians, believed women were at any reasonable risk of infection. In 1993, more than 43,000 AIDS cases, or 12 percent of the epidemic, were among women. The World Health Organization says that 4 million women worldwide will have died of AIDS by the year 2000.



WOMEN & HIV Hear them roar

Women have no special protection—either genital or congenital—against HIV infection. However, some physicians continue to misdiagnose HIV disease in women because of the misperception that women just don't get AIDS.

Women not only get AIDS but are more susceptible, or uniquely susceptible, to some disorders. Women's health-care activists are pressuring the medical system to recognize women's HIV risk and to offer testing and counseling.

Women with HIV should educate their primary-care providers about women's clinical manifestations of HIV disease and urge close monitoring for them. Invasive cervical cancer (see page 20) and pelvic inflammatory disease are specific to women, while candidiasis, genital ulcers, genital warts, and herpes simplex can take special, more virulent forms. See individual entries throughout this section for women's considerations.

Fungal infections

Funguses—simple, single-celled organisms—take such common forms as mushrooms, food molds, and the yeasts used in baking and brewing. Although much less common than bacterial or viral infections, fungal infections can cause both some of the most common and the rarest HIV-related illnesses. Because funguses are so common, in HIV-infected individuals they can cause broad constitutional illnesses—those that affect the whole body—as well as those that are specific to one body part or organ system. Funguses can cause disease in both early- and late-stage HIV infection.

In general, fungal infections tend to be chronic, progress slowly for a period of years, and be somewhat resistant to treatment. Fungal infections of the skin—for example, athlete's foot, jock itch, some forms of dandruff—can occur relatively early in HIV infection and are treatable with over-the-counter antifungal agents. Other fungal infections are much more serious, tend to occur in the later stages of HIV, and are more difficult to treat. Examples include histoplasmosis, cryptococcal meningitis, and coccidioidomycosis.

A variety of antifungal agents are available as standard treatment or are in clinical trials both to treat and to prevent the more serious constitutional illnesses caused by funguses.

.....

Fashion second

ACT UP has given us more than just the tattoo/black leather chic that so often identifies activists. AIDS activism has had a tremendous impact on the American medical establishment. Groups such as ACT UP have been instrumental in lowering the costs of drugs and speeding FDA drug-approval processes. Advocates for other diseases have followed the AIDS community's lead, urging patients to assume active control of their health through self-education and empowerment.

Candidiasis*

Candidiasis, a form of yeast infection, is a common early warning sign of HIV infection. Three types of candidiasis are oral, esophageal, and vaginal.

Oral candidiasis is also known as thrush. It is most often caused by the fungus *Candida albicans* and is characterized by white patches in the mouth and upper throat. Thrush can occur in early to middle stages of HIV infection. Although there may be no noticeable symptoms, some persons experience sore throat, redness of the tongue, and a change in taste.

Late in the course of AIDS, thrush often spreads to the esophagus, the muscular tube leading to the stomach from the throat. Candidiasis of the esophagus is an AIDS-defining illness. Symptoms include chest pain and difficulty swallowing. It can be diagnosed through an endoscopy, a visual examination of the esophagus using a flexible tube. Antifungal agents such as ketoconazole and fluconazole are effective against esophageal candidiasis. (Interestingly, ketoconazole has been shown to be better absorbed by most patients when taken with Coca-Cola!)

Recurrent vaginal candidiasis—also known as a yeast infection—is a serious health problem for immune-compromised women. It is often the first

sign of HIV infection in women. Symptoms include vaginal itching, burning, and thick, white discharge. Recurrent vaginal candidiasis requires treatment with antifungal agents such as fluconazole. Vaginal candidiasis sometimes precedes oral thrush.

Candidiasis is not life-threatening when kept in check but can occur repeatedly in HIV-positive people.

Cryptococcal meningitis*

Cryptococcal meningitis (CM) is a fungal infection that causes inflammation of the meninges, the membranes that cover the brain and spinal cord. This develops after inhaling the fungus *Cryptococcus neoformans*, commonly found in dust and soil that have been exposed to some types of bird droppings. Usually, it is a reactivation after a prior exposure.

The symptoms of cryptococcal meningitis can be vague—fever, blurred vision, mental confusion, headaches, or a stiff or aching neck. Diagnosis is made with a spinal tap (an exam of spinal fluid); a CAT or MRI scan may be needed to rule out other brain lesions. Prompt treatment is important.

Fluconazole is a very effective treatment for CM. Although most patients are started on intravenous amphotericin, most are switched to fluconazole after at least two weeks of treatment. A combination of fluconazole and 5-FC (flucytosine) has been shown to be effective in 70–80 percent of patients treated. For people who have failed other therapies, itraconazole is another drug used in the treatment of CM.

In order to prevent a relapse of CM, lifelong maintenance therapy is necessary. Fluconazole has been shown to be effective and even superior to amphotericin for maintenance.

Some physicians prescribe fluconazole in an attempt to prevent CM when CD4 counts drop below 100, but it is not currently recommended by the CDC because of concerns about drug resistance.

PATIENT ASSISTANCE

Fungal infections

Drug	Pharmaceutical company	Phone number
5-FC (Flucytosine)	Roche Laboratories	800-526-6367
Amphotericin B	Bristol-Myers Squibb	212-546-4000
Fluconazole (Diflucan)	Pfizer	203-441-4162
Itraconazole (Sporanox)	Janssen Pharmaceutica	800-544-2987
Ketoconazole (Nizoral)	Janssen Pharmaceutica	800-544-2987

Histoplasmosis*

Histoplasmosis is a fungal infection caused by *Histoplasma capsulatum*. The disease is most often found in the Midwestern part of the United States, especially in Indiana and the Ohio River Valley.

Symptoms of histoplasmosis include fever, swollen glands, cough, shortness of breath, weight loss, weakness, and anemia. It can be fatal, but in persons with AIDS it can become quite severe. No drugs to prevent the illness are yet available.

Amphotericin B is the primary treatment for histoplasmosis; itraconazole and fluconazole may also be effective. The treatment of choice for maintenance therapy is itraconazole.

Coccidioidomycosis*

Coccidioidomycosis is an uncommon fungal infection (pronounced cock-sidi-OYdo-my-Kosis). In this country, it occurs most often in the Southwest. It is more widespread among people with HIV infection in Mexico and Latin America.

Although coccidioidomycosis may infect any part of the body, it is often concentrated in the lungs. Symptoms may closely resemble those of PCP

(*Pneumocystis carinii* pneumonia): a dry cough, fatigue, shortness of breath, weight loss, and fever. The two illnesses can even occur at the same time. Therefore, if PCP symptoms continue after rigorous anti-PCP therapy, doctors may check for coccidioidomycosis and other fungal infections.

Caused by the fungus *Coccidioides immitis*, coccidioidomycosis usually responds well to the antifungal drug amphotericin B; ketoconazole or fluconazole may be effective against mild cases.

Aspergillosis

Aspergillosis is an unusual cause of infection but may be increasing. It most often causes pneumonia with fever, cough, and shortness of breath. Diagnosis can be made by bronchoscopy, biopsy, or culture of infected areas. The most effective treatment is with intravenous amphotericin B. ▲

▼
▼
▼

Alberto Guzmán has had HIV for several years. Although the percentage of AIDS cases among Latinos, at 17 percent, is not much higher than the percentage of Latinos in the general U.S. population, Guzmán's native Puerto Rico has been devastated by HIV. It ranks sixth among all U.S. states and territories in AIDS cases—just above Illinois, although the Chicago area alone has a larger population than all of Puerto Rico.

HEALTH WATCH

Preventive medicine

Very few "great truths" exist in the world of HIV, where conventional wisdom seems to ebb and flow like the tide.

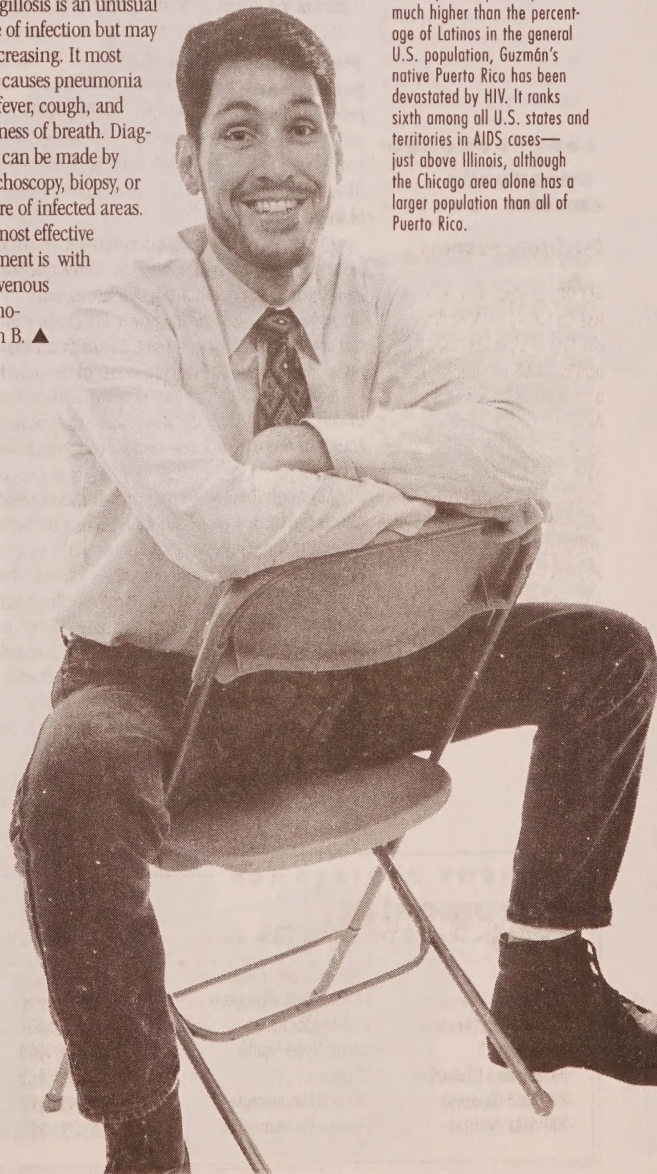
But everyone working with HIV agrees on one "great truth": An essential part of staying healthy is taking advantage of drugs that can help prevent the onset of opportunistic infections.

This kind of preventive medicine, called prophylaxis or prophylaxis, exists for two of the most common and deadly opportunistic infections: *Pneumocystis carinii* pneumonia (PCP) and *Mycobacterium avium* complex (MAC).

PCP prophylaxis. When your CD4 count falls below 200, the Public Health Service recommends beginning PCP prophylaxis. TMP-SMX (Bactrim, Septra) is approved by the FDA as front-line defense, but many people suffer adverse reactions. These people can take the FDA-approved drug aerosolized pentamidine, although many physicians prefer to try dapsone first.

MAC prophylaxis. Recently the FDA approved rifabutin (Mycobutin) for prophylaxis in HIV-positive people whose CD4 cells drop below 100.

Other prophylaxes. No other prophylaxes have been approved by the FDA yet, but trials have shown that many drugs show some effectiveness against a number of illnesses. Ask your physician about prophylaxes for toxoplasmosis, CMV, and candidiasis if you think you're at risk.



Pneumonias

Generally speaking, most lung infections fall under the heading of pneumonias and have the same symptoms: cough, shortness of breath, and fever. Chest pain may also occur. While all these may be symptoms of other illnesses, when they are more severe than usual or occur in someone who has experienced no previous lung problems and is HIV-positive, they may be caused by pneumonia. People with HIV can experience a variety of types of pneumonia, but the most common are *Pneumocystis carinii* pneumonia, tuberculosis, and some common bacterial pneumonias. Standard diagnostic tests performed by a physician can determine the exact nature of the illness.

Pneumocystis carinii* pneumonia (PCP)

Pneumocystis carinii pneumonia (PCP) is the most common and one of the most deadly infections facing people with HIV. PCP is often the first AIDS-defining illness. Drugs that help in the prevention or treatment of this disease are available.

Pneumocystis carinii is a common microscopic organism that rarely causes disease in people with healthy immune systems but can cause havoc in the lungs of HIV-positive people, most often when the CD4 cell count drops below 200 or the CD4 percentage drops below 15 to 20 percent.

Early warning signs are fatigue and shortness of breath. As infection intensifies, rapid breathing, dry cough, fevers, chills, night sweats, and weight loss occur.

Although *Pneumocystis carinii* almost always affects the lung, in rare cases it infects other areas, including the eye, liver, spleen, or bowel.

The U.S. Public Health Service recommends steps to prevent PCP (prophylaxis) when a person's CD4 cell count falls under 200. (Prophylaxis was once recommended when CD4 cell percentage falls below 20 percent but is not generally included in more recent recommendations because the cutoff of 20 percent does not correlate very well with risk). Other warning signs to begin prophylaxis include a rapidly declining CD4 cell count, thrush (oral candidiasis), unexplained persistent fevers over 100° F, or a prior

episode of PCP or other AIDS-defining illness. In children, the recommendations of when to begin PCP prophylaxis differ from those for adults.

Several drugs are effective in preventing or delaying onset of PCP. The most widely tested drug is TMP-SMX, commonly known as Bactrim or Septra. This drug causes side effects, especially fever, rash, nausea, and intense itching in 30–50 percent of patients. Some patients, however, have been successfully desensitized to the side effects of TMP-SMX.

Dapsone is also effective against PCP but is less effective than TMP-SMX. It is usually taken by people who react badly to TMP-SMX, although similar side effects can occur.

Aerosolized pentamidine (AP) is another effective drug. However, research has shown that AP is less effective than TMP-SMX in preventing PCP. Because AP is inhaled as a mist and treats only the lungs, it does not protect other organs from PCP. It is also expensive and inconvenient since it is usually administered at a clinic or physician's office. A hand-held nebulizer is used for administration of AP.

The same drugs that help prevent PCP are also used to treat active infection. Corticosteroids may reduce the likelihood of breathing complications.

For patients not responding to first-line therapies, other options are available. The drug atovaquone (Mepron) has been shown to be as effective and better tolerated than IV pentamidine for mild to moderate PCP; however, it is sometimes poorly absorbed by the body. Clindamycin in combination with primaquine, pyrimethamine, or dapsone with trimethoprim may be an effective second-line treatment for patients intolerant of TMP-SMX or IV pentamidine. NeuTrexin (Trimetrexate Glucuronate) is now available under a Treatment IND (see box) for patients intolerant of first-line PCP therapies, but it is rarely used because side effects and relapse rates are high.

Lymphoid interstitial pneumonia (LIP)*

LIP imitates standard pneumonia but responds to different treatments. It is seen most often in HIV-positive children.

Opportunity knocks

Many HIV-related illnesses are called "opportunistic infections." Why? Because the disease-causing organism is too weak to produce illness without the opportunity offered by a weakened immune system. In fact, some studies have shown that more than two-thirds of all Americans carry *Pneumocystis carinii*, but the organism is powerless to cause pneumonia except in people whose immune systems have been weakened by chemotherapy, organ transplants, or HIV.

PATIENT ASSISTANCE

Pneumonias

Drug	Pharmaceutical company	Phone number
Atovaquone (Mepron)	Burroughs Wellcome	800-722-9294
Clindamycin (Cleocin oral)	The Upjohn Company	800-253-8600
NeuTrexin	NIAID	800-537-9978
Pentamidine (NebuPent)	Fujisawa USA	708-317-8638
TMP-SMX (Bactrim)	Roche Laboratories	800-526-6367
TMP-SMX (Septra)	Burroughs Wellcome	800-722-9294

Diagnosis can be made directly through a lung biopsy, but LIP is also presumed to be present if the illness has not responded to antibiotics, and no specific infectious organisms have been found.

Pneumonia (bacterial)*

An infection of the lung, pneumonia can be caused by a variety of bacteria—an organism called pneumococcus is among them. Two or more bouts of bacterial pneumonia within a 12 month period now account for an AIDS diagnosis under the CDC's 1993 revised AIDS definition.

HIV-infected people sometimes experience bacterial pneumonias early in the course of their infection, before the immune system is more severely damaged. Serious symptoms may develop over days, unlike *Pneumocystis carinii* pneumonia (PCP), which usually takes more time to develop. Also, the frequency of bacterial pneumonia among HIV-infected

persons increases as HIV illness becomes more severe.

Symptoms to watch for include chest pain; a cough that produces yellow or green, thick sputum; fever; and shortness of breath. Diagnosis is usually based on sputum tests and a chest X-ray.

Early use of antibiotics is usually successful in treating bacterial pneumonias. A vaccine called Pneumovax also helps to prevent pneumococcal pneumonia and is recommended by the CDC. ▲

▼
▼
▼

George Williams, a former injection-drug user who has been clean for 20 years, considers himself lucky: He says he shared needles consistently but never contracted any blood-borne illnesses. Now, as president of the Chicago Recovery Alliance, a needle-exchange program, he hopes to pass his good fortune on to others. Injection-drug users are now one-third of the HIV epidemic. Several studies have come to the same conclusion, however—needle exchange saves lives.

CLINICAL TRIALS

Getting testy

Clinical trials test experimental drugs for their effectiveness in treating illnesses. HIV-related clinical trials exist that test drugs to treat primary HIV infection, its associated opportunistic infections, and other HIV-related medical conditions.

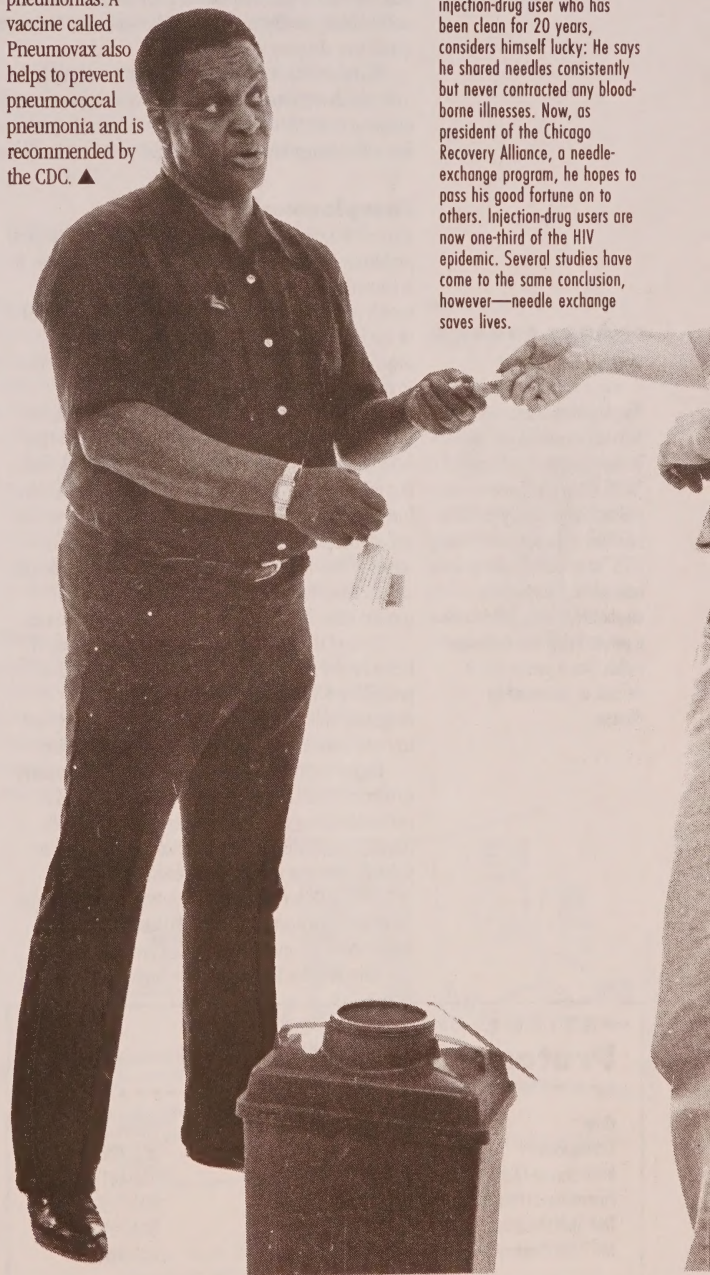
A clinical trial almost always has inclusion and exclusion criteria for participants. This means that the participant must meet medical requirements—such as a specific CD4 cell count range or a diagnosis with a particular opportunistic infection—to qualify for the trial.

Enrollment of women and people of color is especially important to the success of clinical trials.

One major advantage of enrolling in a clinical trial is that patients usually receive the experimental drug and necessary medical tests free of charge. However, a disadvantage is that patients sometimes may not know whether they are being given the drug or a placebo, a "fake" pill given to a portion of participants against which the drug's effectiveness can be measured. Also, sometimes it is difficult to predict whether a patient will experience serious side effects.

Trials may be independently sponsored, typically by a pharmaceutical manufacturer or by a medical research institution. However, the most common HIV-related clinical trials are nationally organized networks such as the federal government's AIDS Clinical Trials Group (ACTG) and the Terry Bein Community Program for Clinical Research on AIDS (CPCRA), and the Community-Based Clinical Trials Network (CBCN), sponsored by the American Foundation for AIDS Research.

Some studies, particularly those conducted by pharmaceutical companies, pay participants a stipend. Be sure to ask! For more information about clinical trials in your area, call 1-800-TRIALS-A.



Protozoal (parasitic) infections

Protozoa are microscopic animals, most of them single-celled and recognized by the fine hair- or whip-like features with which they move. They occur in soil and water, on dead organic matter, and on bacteria. Some well-known, mostly tropical, diseases are most commonly thought of in association with protozoa: malaria, giardiasis, sleeping sickness.

Some protozoa are extremely common throughout the population and cause health problems only in individuals with weakened immune systems. For example, the parasite that causes toxoplasmosis—an AIDS-defining condition—is estimated to be present in more than half the adults in the United States, although very few suffer symptoms of it. It is found most frequently in domestic cats and undercooked meat.

Toxoplasmosis*

Toxoplasmosis (toxo) is a major cause of neurological problems in people with AIDS, especially in Europe. It is caused by the parasite *Toxoplasma gondii*, commonly found in undercooked meat. Up to 50 percent of the U.S. population has been infected with this organism, but the infection usually remains dormant in people with normal immune function.

Almost all cases of toxoplasmosis in HIV-infected individuals occur in people with fewer than 100 CD4 cells. Most toxoplasmosis infections occur in the brain, but infection may also occur in the heart, liver, colon, lungs, or other organs. Toxoplasmosis of the brain is called toxoplasmic encephalitis. Symptoms may resemble those of other HIV-related illnesses and include a persistent, dull headache, subtle alterations in mental state, fever, seizure, or stroke-like syndromes.

Toxo of the brain can be difficult to diagnose. A brain biopsy is the most accurate method, but this procedure is risky. Physicians usually make the diagnosis on the basis of a positive toxo antibody test in combination with a CAT scan or MRI brain scan.

Eighty to 90 percent of patients with toxo respond to therapy. Standard treatment is sulfadiazine plus pyrimethamine. Atovaquone may be effective with minimal side effects in treating toxo of the brain in patients resistant to standard treatment.

TMP-SMX is often the first choice for toxo prophylaxis. Also, pyrimethamine with dapsone or sulfadoxine may be equally effective in preventing toxo.

Relapse rates for patients are high, so people

treated for toxo must remain on long-term medication. This usually involves taking lower dosages of the drugs originally prescribed to treat the acute infection.

Cryptosporidiosis*

Cryptosporidiosis is a disease characterized by severe, watery diarrhea that can last for months. Other symptoms may include weight loss, abdominal cramps, nausea, vomiting, fever, and headache. This illness usually affects people with fewer than 100 CD4 cells.

Cryptosporidium, the intestinal parasite that causes the disease, is common among farm and domestic animals. Highly infectious, it can be transmitted through contaminated food or water.

Symptoms usually develop gradually and fluctuate in severity.

Severe cryptosporidiosis is life-threatening when it causes rapid weight loss and depletes nutrients; patients need to drink a lot of fluids and eat a high-calorie diet. Nutritional supplements may be prescribed.

Because many parasites can cause severe diarrhea, and because more than one can be present, determining which one is causing illness can be complicated. Several stool samples may have to be taken.

Cryptosporidiosis is difficult to treat. However, paromomycin may be an effective therapy. Maintenance therapy with paromomycin may prevent relapse in some patients. Azithromycin may have some beneficial effect in the short term. Symptoms may be relieved by using anti-diarrheal medication such as Imodium, Lomotil, or Kaopectate.

Isosporiasis*

Isosporiasis is an opportunistic infection that results in chronic watery diarrhea. The cause is an organism called *Isospora belli*. It is most often carried in contaminated food or water, especially in Latin America or developing countries.

Isosporiasis is diagnosed by microscopic examination of a person's stool; treatment is with TMP/SMX (Bactrim, Septra). TMP/SMX or a combination of sulfadoxine and pyrimethamine are used to prevent return of the infection. ▲

PC revisited

People with diseases such as AIDS or hemophilia usually dislike references such as "AIDS victim" or "hemophilic." Instead, they prefer to be called a "person with HIV or AIDS" or a "person with hemophilia." These terms emphasize that an individual is a person living with a disease rather than a person who is defined or victimized by disease.

PATIENT ASSISTANCE Protozoal infections

Drug	Pharmaceutical company	Phone number
Atovaquone	Burroughs Wellcome	800-722-9294
Azithromycin (Zithromax)	Pfizer	203-441-6148
Paromomycin (Humatin)	Parke-Davis	800-755-0120
TMP-SMX (Bactrim)	Burroughs Wellcome	800-722-9294
TMP-SMX (Septra)	Roche Laboratories	800-526-6367

Neurological manifestations

HIV infection can affect the brain and the rest of the nervous system either by damaging them directly or by allowing other infectious agents to damage them. The brain and the spinal cord make up the central nervous system, while the nerves that carry sensory messages to the brain and commands back to the muscles constitute the peripheral nervous system.

Thirty to 40 percent of people with AIDS will eventually experience some form of neurological difficulty. The cells of the central nervous system itself are thought to be able to be infected by HIV, leading to such complications as AIDS dementia complex. Opportunistic infections of the central nervous system can include toxoplasmosis and meningitis. Severe headaches, sudden changes in vision, and loss of feeling or movement can indicate neurological difficulties and should be examined by a physician.

Dementia* (AIDS-dementia complex)

Dementia refers to general mental deterioration leading to confusion, memory loss, and decreased intellectual function. Causes include HIV infection, head injury, stroke, severe vitamin deficiency, chronic alcohol or drug abuse, or any disease affecting the brain. HIV infection alone may cause dementia, as can several other AIDS-related conditions. (See toxoplasmosis, PML, cryptococcal meningitis, lymphoma.) HIV may infect the brain and other parts of the nervous system, where it often remains inactive. At first, mild abnormalities are detected only with careful testing. Later, patients may develop difficulty in concentration, poor memory, slowness in thinking, and inability to perform complex tasks. Loss of coordination, weakness, and trouble walking may follow. In the most advanced form, a person is bedridden and cannot maintain control of bladder or bowels.

Because there is no specific test for HIV dementia, other causes must be ruled out, especially treatable opportunistic infections. Spinal tap, CAT scan, or MRI may be needed. AZT may reduce symptoms of AIDS-dementia complex and prolong life for PWAs with this condition. Social support is especially important.

Progressive multifocal leukoencephalopathy (PML)*

PML is a brain disorder. Early warning signs of this AIDS-defining illness include headaches, forgetfulness, double vision, and difficulty walking or speaking. More serious signs and symptoms include loss of vision, seizures, and paralysis. These problems are similar to other neurological problems.

This infection occurs in up to 4 percent of persons with AIDS and progresses most rapidly in persons with CD4 counts less than 50.

Diagnosis is made by CAT scan or MRI. A brain biopsy—removal of some brain tissue—is required for confirmation. Because other illnesses have similar signs and symptoms, PML might be misdiagnosed as toxoplasmosis or AIDS-dementia complex.

There is no approved treatment, although AZT may cause some clinical improvement.

Neuropathy

Neuropathy is the general term for any disease of peripheral nerves—those that control muscles and sensation. Symptoms include burning pain (especially in the feet), loss of sensation, numbness, tingling, and muscle weakness or even paralysis.

Like myopathy (muscle weakness), neuropathy can be due to HIV itself or can be a side effect of drugs—especially ddI and ddC. Sometimes CMV can cause neuropathy. Treatment is frustrating. Some patients find improvement of their symptoms with antidepressants, seizure medications, or acupuncture.

Encephalitis

Inflammation of the brain is called encephalitis. Usually it is due to an infection, but it can also result from drug reaction or other disorders. Symptoms include fever, headache, and unclear thinking. Encephalitis may accompany meningitis—an inflammation of membranes that cover the brain. ▲

●●●●●●●●●●

Veni vidi vending

From bars to truckstops to gas-station bathrooms, vending machines have been used to sell everything from soda pop to condoms to tampons to combs. Still, who would have guessed that in Berlin in 1988, vending machines carrying sterile syringes would be used to reduce the spread of HIV among injection-drug users?



"DEEP DOWN IN MY SUBCONSCIOUS, THERE'S A KIMBERLY BERGALIS TRYING TO GET OUT AND SEE SOMEBODY!!"

Malignancies (cancers)

Malignancies, or cancers, arise from the multiplication of abnormal body cells, a process that can be set in motion by environmental agents, radiation, or inherited tendencies. In contrast, infections arise from the multiplication of substances that are considered foreign to the body. Cancerous cells can form tumors—swollen growths or collections of cells—that are sometimes called lesions. Chemotherapy and radiation are the two most frequent treatments for cancers. They try to destroy cancerous cells while doing as little harm as possible to healthy cells.

While HIV-positive individuals may experience the same types of cancers as those without HIV, three cancers in particular are associated with HIV infection: Kaposi's sarcoma, invasive cervical cancer, and non-Hodgkin's lymphoma.

Kaposi's sarcoma (KS)*

Kaposi's sarcoma (KS) is a cancer characterized by abnormal growths of blood vessels which develop into purplish or brown lesions.

KS can appear anywhere on the body, but most often appears on the nose, arms, legs, feet, and the roof of the mouth. Its lesions usually do not hurt or itch. The cancer progresses over time, with the lesions increasing in size and appearing in multiple sites at once. A definitive diagnosis requires biopsy.

KS is the most common tumor associated with HIV, particularly in gay men. The cause is unknown, but research suggests it may be due to a sexually transmitted agent, but that agent has yet to be identified.

KS can appear in internal organs, especially the lungs and gastrointestinal tract. When KS affects internal organs, it can cause stomach problems, coughing, and shortness of breath. KS tumors that obstruct the lymph nodes cause lymphedema, a swelling of the limbs.

There are a variety of therapies to treat KS. Radiation therapy can reduce painful lesions and relieve swelling; laser surgery is useful for tumors in the mouth; and local freezing can kill KS cells and enable tumors to fade.

The treatment of KS depends on several factors. Individuals with CD4 counts greater than 200 can benefit from a combination of AZT and interferon. Those with CD4 counts less than 200 may not respond as well. Treatment can be local or systemic. Local includes cryosurgery (freezing), radiation, or injection with a chemotherapeutic agent—vinblastine.

Systemic treatment is chemotherapy. Liposomal-doxorubicin is currently experimental, reserved for disease that responds to nothing else. No treatment affects the cause of KS, which is unknown. The treatments are mainly cosmetic or for symptomatic relief, especially when KS appears in the lungs.

Lymphoma*

Lymphoma is a cancer that starts in the lymph nodes.

The two major types of lymphoma are Hodgkin's disease and non-Hodgkin's lymphoma (NHL). Central nervous system lymphoma is a different syndrome. It usually appears only in the brain. Lymphoma of the brain is considered an AIDS-defining illness unless HIV infection is completely ruled out.

An intensive chemotherapeutic drug regimen has been shown to be of some benefit to PWAs diagnosed with lymphoma, but in people with CD4 counts less than 200, the prognosis is poor.

Invasive cervical cancer*

Cervical cancer is a common form of cancer among women, and the conditions that lead to it appear to be more common in HIV-positive women. Cervical cancer in HIV-positive women often advances more rapidly and is more difficult to treat than in HIV-negative women.

Prevention of cervical cancer is one reason doctors recommend Pap smears, which allow detection of abnormal cells by microscopic examination of material collected during a pelvic exam. The CDC recommends Pap smears twice a year in women who are HIV-positive.

When abnormal cells are present, they may indicate infection, cancer, or a pre-cancerous condition known as dysplasia. Dysplasia may progress to localized cancer.

When cancer cells grow into other tissue, they are termed "invasive." Studies show dysplasia is more common in HIV-positive women. Invasive cancer of the cervix may thus occur more readily in these women and may be more severe.

The treatment depends on the stage of the disease and the aggressiveness of the cancer. Often a woman must undergo colposcopy, which is similar to using a microscope to examine the cervix.

Cryosurgery—or the use of a freezing technique—may eliminate early disease, but sometimes surgical excision or hysterectomy (removal of the uterus) might be recommended.

All women—especially those who are HIV-

Mammary loss

Few HIV-positive people know that they can become unable to digest lactose, a sugar found in milk and milk products such as ice cream, cheese, or cream. This can lead to diarrhea, gas, or other intestinal discomfort. For some, yogurt can still be digested. To continue to get the nutrition available in dairy products, try purchasing lactose-free milk or using such products as Lactaid or Dairyase when consuming milk or any of its products.

positive—should receive regular gynecological care, including Pap smears.

Non-Hodgkin's lymphoma (NHL)*

Non-Hodgkin's lymphoma (NHL) is a cancer that causes rapid, abnormal growth among lymphocytes—infection-fighting cells that are an important part of the body's immune system. NHL is occurring increasingly in people with HIV and usually occurs in advanced stages of HIV infection.

NHL can occur in many different parts of the body. In people with HIV, the most common sites of disease are the central nervous system and bone marrow, although other areas affected include the gut, liver,

lungs, lymph nodes, and meninges—the lining of the brain and spinal cord.

Common symptoms of NHL resemble many other HIV complications—fever, weight loss, and night sweats—as well as swollen spleen and lymph nodes. Symptoms of CNS lymphoma include headaches, memory loss, confusion, and problems with speech or walking. These symptoms may resemble those of toxoplasmosis. If blood tests and X-rays are not able to distinguish NHL from toxoplasmosis, a brain biopsy—the removal of a small piece of brain tissue for examination—is necessary for definitive diagnosis.

Chemotherapy has been successful in treating NHL, but it often damages an already suppressed immune system. Because side effects of chemotherapy can be severe and relapse is frequent, risks and benefits must be carefully weighed. ▲



There is nothing average about Betty Jean Pejko. Since her AIDS diagnosis in April 1988, she has appeared on billboards, led ACT UP marches, and spoken passionately about HIV in public and private. Her partner Jorge and their six-year-old daughter Maggie, both HIV-negative, offer the kind of unconditional support that has helped keep her CD4 cells hovering above 900 after years of infection. The epidemic is spreading faster among heterosexuals than among any other group. Four percent of U.S. AIDS cases reported in 1989 were from heterosexual transmission, but in 1993 that number rose to 15 percent of all reported cases—that's an increase of almost 400 percent.



ORAL HEALTH

Put your medication where your mouth is

At least 40 oral problems have been identified as being more severe in HIV-infected persons. These problems may begin with especially bad breath, usually caused by an overgrowth of bacteria. Some of the most common HIV-related oral problems are gingivitis, oral hairy leukoplakia, periodontitis, thrush, KS, aphthous ulcers, herpes lesions, dry mouth, and salivary gland enlargement.

It is important to monitor your oral health with regular visits to your dentist, as some opportunistic infections are first detected through examining the mouth. Daily brushing and flossing are also especially important in maintaining good oral health. Ask your dentist about Peridex—a prescription mouth rinse that can reduce oral bacteria, gingivitis, and periodontitis.

Common HIV-related oral problems

Oral Hairy Leukoplakia (OHL)—A viral infection identified by white, hair-like patches in the mouth—particularly on the sides of the tongue. OHL is generally not painful or contagious. Acyclovir or cryotherapy (a freezing technique) may help control severe cases.

Gingivitis—An inflammation, swelling, and soreness of the gums. Regular brushing, flossing, Peridex mouth rinse, and professional dental care can help control the condition. May lead to HIV-related periodontitis.

Periodontitis—Severe breakdown of the gums, causing bad breath, bleeding of the gums, soreness of gums and teeth, and tooth loss.

Aphthous ulcers (canker sores)—Small, painful white sores on the mouth or gums. These may respond to steroids.

See also Candidiasis (thrush), Herpes simplex virus, and Kaposi's sarcoma.

Skin manifestations

Mild skin problems are common in HIV-positive persons, affecting about 90 percent at some point. They may serve as an early warning sign of HIV infection or progression. During the early and middle stages of HIV infection, they are easily treatable, although they tend to become recurrent and may require continuing treatment to control. In advanced HIV disease, skin problems can become more severe and harder to treat. Skin disorders fall into four categories: infections (bacterial, fungal, or viral), allergic reactions, scaly or bumpy skin disorders, and cancers.

Seborrheic dermatitis

Seborrheic dermatitis (SD) is one of the most common skin problems among people with HIV. SD produces patches of itchy, red skin. Its cause is not completely understood. SD can affect the face, groin, chest, armpits, and eyebrows. It causes dandruff when it affects the scalp. The affected area is usually reddish with greasy scales. Regular use of dandruff shampoo is the best treatment for the scalp. Other areas can be treated with steroid and antifungal creams. Severe cases may require oral antifungal medication such as ketoconazole.

Folliculitis

Folliculitis, an infection of hair follicles, resembles "heat rash." The three types are staphylococcal, eosinophilic, and fungal. These conditions cause itchy red bumps around hair follicles on various parts of the

body. Each kind of folliculitis requires a different kind of treatment: antibiotics are used for staphylococcal, ultraviolet light treatments are used for the eosinophilic or "allergic" form, and oral antifungals may be used for fungal infections.

Psoriasis

HIV-positive individuals with psoriasis may notice a worsening of this skin condition. Symptoms resemble those of seborrheic dermatitis, but scaling is more severe. The knees, elbows, and lower back are commonly affected. Steroid creams may help. Many cases improve when antivirals are begun.

HIV-infected people may have many other skin problems, including rashes due to drugs, exaggerated reactions to insect bites, and photodermatitis (sensitivity to direct sunlight, which can lead to sunburn). ▲

HIV-RELATED CONDITIONS

Weight disorders

Severe weight loss, whether related to an infection or to general HIV infection, can have several causes and many potential treatments. Sudden weight loss without any explanation can be a sign of disease progression. Weight loss should be addressed early: Don't wait too long to see your physician if you experience a quick weight drop.

Wasting syndrome*

AIDS wasting syndrome is a loss of 10 percent or more of body weight with no explanation other than HIV infection. In addition, a diagnosis of wasting syndrome includes diarrhea or fever and weakness. Contributing factors include malabsorption due to oppor-

tunistic infections or diarrhea and a lack of adequate food intake because of decreased appetite or vomiting.

Protein-calorie malnutrition (PCM) often accompanies wasting. PCM results when intake of protein or total calories is inadequate to meet the body's energy needs. Loss of lean muscle mass can then be sudden.

There are several approaches to control wasting. Severe diarrhea can sometimes be controlled by Kaopectate, Lomotil, or Imodium. Appetite may be stimulated by using either Megace or Marinol. Some individuals may require liquid food supplements that are high in calories and protein. Some supplements have specially formulated fats that are less likely to cause diarrhea in the HIV-infected person. ▲

PATIENT ASSISTANCE

Weight disorders

Drug	Pharmaceutical company	Phone number
Dronabinol (Marinol)	Roxane Laboratories	800-848-0120
Megestrol acetate (Megace)	Bristol-Myers Squibb	800-788-0123

Potential drug interactions

By Mark Mascolini

Some drugs used to treat either HIV itself or opportunistic infections can interact with other drugs—both

prescription and over-the-counter. This table indicates some of the most common possible interactions and is not intended to be exclusive. ▲

Class	HIV/OI Drug	Potential Reactions
Antivirals	AZT (Retrovir) ¹	R: Acetaminophen, Acyclovir, Amphotericin B, Aspirin, Dapsone, Doxorubicin, Flucytosine, Indomethacin, Interferon, Pentamidine, TMP-SMX, Vinblastine, Vincristine ⚡: Rifampin ↔: Phenytoin ⚡: Probenecid, TMP-SMX ⚡: Ganciclovir
	ddC (Hivid)	R: Aminoglycoside antibiotics, Amphotericin B, Foscamet ⚡: Chloramphenicol, Dapsone, Disulfiram, Ethionamide, Hydralazine, Isoniazid, Metronidazole, Phenytoin, Ribavirin, Vincristine ⚡: ddI, Pentamidine
	ddI (Videx) ²	R: Alcohol, Antacids, Pentamidine ⚡: Ganciclovir ⚡: Tetracycline, ddC ⚡: Dapsone, Ketoconazole, Quinolone antibiotics
	Foscamet (Foscavir) ³	⚡: Aminoglycoside antibiotics, Amphotericin B, Pentamidine R: ddC
	Ganciclovir (Cytovene)	⚡: Amphotericin B, Dapsone, Doxorubicin, Flucytosine, Imipenem-Cilastatin, Pentamidine, TMP-SMX, Vinblastine, Vincristine, Zidovudine R: Cyclosporine ⚡: Probenecid
Antibiotics (Drugs that are used to fight bacteria. TMP-SMX is also effective against PCP.)	Azithromycin (Zithromax)	⚡: Triazolam ⚡: Antacids ⚡: Anticoagulants (such as Warfarin) ⚡: Carbamazepine, Cyclosporine, Digitalis, Phenytoin, Theophylline
	Isoniazid (INH, Rifamate)	R: Alcohol, Carbamazepine, Cycloserine, Disulfiram, Ethionamide, Rifampin ⚡: Benzodiazepines, Diazepam, Lorazepam, Phenytoin ⚡: Antacids ⚡: Warfarin ⚡: Corticosteroids
	Rifampin (Rifadin, Rimactane)	R: Alcohol, Halothane, Isoniazid ⚡: Ketoconazole ⚡: Probenecid ⚡: Anticoagulants, Anticonvulsants, Barbiturates, Beta-adrenergic blockers, Cardiac glycosides, Chloramphenicol, Clofibrate, Corticosteroids, Cyclosporine, Dapsone, Diazepam, Digitalis, Disopyramide, Estrogens, Methadone, Mexiletine, Narcotic analgesics, Oral contraceptives, Phenytoin, Progesterone, Quinidine, Sulfonyleureas, Theophylline, Tocainide, Verapamil, Warfarin
	TMP-SMX (Bactrim)	⚡: Anticoagulants, Sulfonyleureas, Warfarin R: Cyclosporine ⚡: Phenytoin
Antifungals (Drugs that fight fungal illnesses such as cryptococcal meningitis.)	Amphotericin B	R: Aminoglycoside antibiotics, Cisplatin, Corticosteroids, Cyclosporine, Diazepam, Digitalis, Ganciclovir, Muscle relaxants, Polymixin B, Vancomycin ⚡: Foscamet ⚡: Probenecid
	Fluconazole (Diflucan)	⚡: Hydrochlorothiazide, Rifampin ⚡: Cimetidine ⚡: Cyclosporine, Phenytoin ⚡: Warfarin ⚡: Sulfonyleureas, Tolbutamide
	Itraconazole (Sporanox)	⚡: Antacids, Anticonvulsants, Rifampin, Terfenadine
	Ketoconazole (Nizoral)	⚡: Antacids, Anticholinergics, Cimetidine, Ranitidine R: Alcohol ⚡: Phenytoin ⚡: Isoniazid, Rifampin ⚡: Anticoagulants, Sulfonyleureas, Warfarin ⚡: Cyclosporine, Terfenadine
Antiprotozoal/Antiparasitic (Drugs that fight illnesses such as PCP.)	Atovaquone (Mepron) ⁴	⚡: Acetaminophen, Acyclovir, Antidiarrheals, Benzodiazepines, Cephalosporin antibiotics, Laxatives, Opiates ⚡: Fluconazole, Prednisone
	Pentamidine (Pentam, NebuPent)	R: Aminoglycoside antibiotics, Amphotericin B, Capreomycin, Cisplatin, Methoxyflurane, Polymixin B, Vancomycin ⚡: Foscamet, Ganciclovir
	Pyrimethamine	R: Chloroquine, Dapsone, Lorazepam, Sulfonamides, TMP-SMX ⚡: Para-aminobenzoic acid

- ⚡: decreased blood level of HIV/OI drug
- ⚡: decreased blood level of interacting drug
- ⚡: decreased absorption of HIV/OI drug
- ⚡: decreased absorption of interacting drug
- ⚡: increased blood level of HIV/OI drug
- ⚡: increased blood level of interacting drug

- ⚡: decreased clearance of HIV/OI drug
- ⚡: decreased clearance of interacting drug
- ⚡: decreased efficacy or activity of HIV/OI drug
- ⚡: decreased efficacy or activity of interacting drug
- ⚡: increased efficacy or activity of interacting drug
- R: increased risk of drug-associated toxicity

- ⚡: combination of two drugs not recommended by manufacturer
- ⚡: combination of two drugs should be avoided if possible or unless benefits outweigh risks.
- ⚡: two drugs alter each other's metabolism
- ↔: levels of interacting drug may fluctuate

Some categories may overlap: a drug that increases another drug's blood level may increase that drug's risk of toxicity. Such categories are kept separate to reflect how they are usually cited by the manufacturer or other source. KEY: ¹ Risk of toxicity may be increased by co-administration of drugs that are nephrotoxic or cytotoxic or that interfere with the number or function of red or white blood cells. ² Drugs that may cause pancreatitis or peripheral neuropathy may increase the risk of those side effects in individuals taking didanosine. ³ Co-administration of foscamet with any other drug could in theory alter its efficacy or toxicity. Foscamet decreases levels of calcium and so should be used cautiously with other drugs that decrease calcium levels. ⁴ Atovaquone is highly bound to plasma protein and so its effect may be diminished if it is given with other drugs that are highly bound to plasma protein. NOTES: Most listed drug interactions do not represent absolute contraindications; some represent reports of only a few cases. Complete product information should be consulted to verify relative danger of the interaction. Both specific drugs and some manufacturers may report interactions with single agents or entire classes.

Safer sex: what is it?

By Scott Williams

The definition of safer sex varies from one person to another. For instance, some people feel comfortable performing oral sex on a man without the use of a condom, while other people do not. Experts are divided on what, if any, risk is involved because some activities lie in a gray area considered "possibly risky" for HIV infection. Sexually active individuals must make some important decisions about what they want to do in the bedroom. The terms and facts below may help you think about how you want to define safer sex.

Risk is a term associated with a variety of activities relating to HIV infection. HIV is found in body fluids—blood, semen, vaginal secretions, and breast milk. A person is at risk of becoming infected with HIV when he or she engages in certain activities that bring his or her bloodstream into contact with



More and more people are learning how to play safer and enjoy it. The uncensored 17" x 22" poster and safer sex postcard from TPA Network are two ways to let your guests know that safer sex is a fact of life in your house. Posters and postcards are free. All you pay is the cost of shipping and mailing tube or envelope. Send a check payable to TPA Network for \$3 for one poster; \$4 for five posters, or \$10 for 10.

For free postcards, just send a 5" x 7" self-addressed envelope with 52 cents postage for 10 postcards, or 75 cents postage for 25 postcards. Send your checks to Safe Sex Poster, TPA Network, 1340 W. Irving Park Rd., Box 259, Chicago IL 60613. Please: no phone or fax orders. Requests received without postage cannot be processed.

ORAL SEX

With or without a love glove...?

The great safer sex debate rages on.... Is it safe or unsafe to perform oral sex on a man? Actually, the answer may lie somewhere between the two extremes.

HIV has been detected in the pre-cum of HIV-positive men—and in greater volume in the cum itself. The most likely points of entry for HIV when performing oral sex are the mouth and the gums—not the esophagus or the stomach. So the issue of swallowing cum may be less important than whether the mouth and gums are unhealthy or have small cuts or sores. For instance, gingivitis or improper brushing and flossing the teeth may make an individual performing oral sex more susceptible to HIV infection.

Most U.S. AIDS educators encourage using a latex condom when performing oral sex on a man, yet one study estimated that fewer than 5 percent of gay men actually do so. Luckily, saliva has been shown to have some inhibitory effects on HIV infection, which further decreases the chance that a person with healthy gums giving a blow job will become infected. In fact, very few AIDS cases have been linked conclusively to either performing or receiving oral sex. European and Canadian AIDS educators give thumbs up to oral sex.

Ultimately, every individual who engages in oral sex with a man should make an informed, personal decision about what he or she is comfortable doing.

any of the fluids in which HIV may be found. (Described below are certain behaviors and their generally accepted categories for risk of HIV infection.)

Exposure to HIV means that a person has engaged in a behavior that puts him or her at risk for infection with HIV. Exposure to HIV does not necessarily lead to infection. For instance, having unprotected sex one time with an HIV-positive person does not mean that you will become infected, but the possibility certainly exists that infection could occur.

Infection with HIV means that the virus has entered the bloodstream and taken root, the body has begun to produce HIV antibodies, and the person will test HIV-positive after two weeks to six months.

Behaviors considered high-risk for contracting HIV

- Anal or vaginal sex without a latex condom
- Oral sex on a man to ejaculation
- Oral sex on a woman during menstruation
- Fisting without a latex glove
- Watersports in the mouth or on open sores
- Sharing dirty needles or drug-injection equipment

The gray area: behaviors with an uncertain amount of risk

- Anal or vaginal sex with a latex condom
- Oral sex on a man not to ejaculation (see sidebar)
- Oral sex on a woman not during menstruation
- Wet kissing

Behaviors considered to have little or no risk

- Massage
- Mutual masturbation
- Dry kissing
- Bondage
- Body-to-body rubbing
- Nipple play
- Licking and sucking healthy areas of skin
- Sex toys (dildos, vibrators) that are not shared

Only you can decide what activities you engage in and what levels of responsibility you need for protecting yourself. The decision requires self-education and personal exploration of what activities you feel comfortable with. It is ultimately a very personal decision. However, by arming yourself with latex condoms, dental dams, water-based lube, and spermicides that kill HIV, you may feel more confident about any choice you make. ▲

Commonly used HIV terms

Acquired Immune Deficiency Syndrome (AIDS)—a life-threatening collection of illnesses due to HIV infection.

Acute infection—any infection that begins suddenly, with intense or severe symptoms, is called acute. If the illness lasts more than a couple of weeks, it is called chronic.

Antibiotic—a drug used to combat bacterial infection by killing bacteria or slowing their growth.

Antibody—a protein that identifies, neutralizes, or kills harmful toxins. HIV can often be detected in the body by the presence of HIV antibodies.

Antigen—any substance capable of stimulating an immune (antibody) response.

Antiviral—a substance or process that destroys a virus or suppresses its ability to reproduce.

Antiretroviral—drugs that fight a retrovirus. HIV is a retrovirus; AZT, ddI, ddC, and proteinase inhibitors are a few antiretrovirals.

Asymptomatic—without symptoms.

B-cell—a type of cell in the immune system that fights infection primarily by making antibodies.

Biopsy—any procedure in which a sample of tissue is removed from the body for examination in a laboratory. The sample is usually examined under a microscope to see if there are signs of a disease process. Biopsies are commonly used to diagnose cancer and to help identify causes of infection.

Chronic—continuing, persistent, or recurring.

CD4—a protein embedded in the cell surface of certain T-lymphocytes, called CD4 cells; HIV invades cells by first attaching to the CD4 protein.

CD4 cell count—the actual number of T-cells (lymphocytes) in a cubic millimeter of blood. The CD4 cell count is significantly lower in people whose immune systems have been affected by HIV.

CD8—a protein embedded in the cell surface of certain T-lymphocytes. CD8 cells are also called cytotoxic T-lymphocytes (CTLs).

Chemotherapy—the use of drugs to combat disease, especially cancer.

Chronic infection—an infection that persists for longer than a couple of weeks or recurs over time.

Cytokine—a chemical messenger secreted by immune cells to regulate immune activity.

Cytotoxic—damaging to cells.

Dermatitis—inflammation of the skin.

Disseminated—scattered throughout the body.

ELISA—Enzyme Linked Immunosorbent Assay: a testing method to detect antibodies to HIV.

HIV—Human immunodeficiency virus: the retrovirus recognized as the cause of AIDS. HIV may

work with unidentified cofactors to cause AIDS.

Immune system—the mechanism in the body that fights infections.

Immunosuppression—reduced performance of the body's immune system.

Incubation period—the time between exposure to an infection and the first signs of the body's response. In HIV infection, this time usually ranges from a few weeks to six months.

Infection—the invasion of the body by bacteria, fungi, viruses, or other organisms.

Inflammation—when tissue becomes swollen, red and heated, usually in response to infection.

Intravenous—within or into the veins. Intravenous drugs are injected directly into the veins.

Invasive—an invasive disease is one in which organisms or cancer cells are spreading throughout the body; an invasive medical procedure is one in which a device is inserted into the body.

Laboratory marker—results of any test used to monitor a disease process or progress.

Lymph nodes—bean-sized organs that filter lymph, a fluid that carries lymphocytes.

Lymphadenopathy—swelling or tenderness of the lymph glands.

Lymphocyte—a type of white blood cell.

Malabsorption—failure of the intestines to absorb food or nutrients properly.

Neuropathy—a tingling or burning sensation of the nerves, usually in the hands or feet.

Pap smear—microscopic examination of cells obtained by scraping the lining of the vagina and the cervix.

Pathogen—an organism or material capable of causing disease.

Peripheral neuropathy—see neuropathy.

Prophylaxis—a treatment intended to preserve health and prevent the spread of disease.

Seroconversion—the time at which a person's antibody status changes from negative to positive.

Suppressor T-cell (T8, CD8)—a subset of T-cells that halt antibody production and other immune responses.

Symptomatic—a person who doesn't feel well and has medical problems that can be observed or measured is said to be symptomatic.

Systemic—affecting the entire body.

T-lymphocytes—white blood cells that participate in cell-mediated immune reactions. CD4 cells and CD8 cells are both types of T-cells.

Western Blot—a test for specific antibodies, more specific and expensive than the ELISA test. ▲

Playing safe

Remember your parents giving you the birds-and-the-bees talk? How about an STDs/AIDS talk? Well, a new game in Germany called *Sexecke* helps parents and kids talk openly about sexuality, sexual behavior, STDs, AIDS, pregnancy, contraception, and love. Somebody call Parker Brothers.

Alphabet soup: anti-HIV drugs

By Timothy Frick

When you are HIV-positive, deciding what drug regimens will work best for you can be confusing, like looking into a bowl of alphabet soup. The combination of numbers and letters that make up these drugs' monikers can be downright frustrating. This is particularly true when it comes to antiretrovirals, the drugs that directly combat the human immunodeficiency virus.

In addition to their confusing names, what these drugs actually do, how they work, or how effective they are may not be completely clear. Plus, those that have been around the longest sometimes spark the most skepticism, while upcoming treatments have not yet been tested enough to determine their usefulness. This can add to the confusion.

A visit to your doctor—as well as talking with other HIV-positive people—can help you find the best and most affordable answers to your needs. He or she can explain to you the advantages or disadvantages of various therapies.

Ultimately, however, the final decision about antiretroviral therapy is yours. Here is some information that can help you digest your knowledge of the antiretroviral alphabet soup.

Advantages

Studies have shown that antiretroviral therapies can provide many benefits. Not only can they prolong life and improve many immune system functions, such as CD4 counts and p24 antigens, they can also delay the

onset and lessen the severity of opportunistic infections like *Pneumocystis carinii* pneumonia and the neurological complications of toxoplasmosis. They may offer a critical window of continuing good health until more effective therapies are available.

Disadvantages

For some people, antiretrovirals can have disadvantages that anyone who is considering using them should be aware of. First of all, they may cause serious side effects, some of which have been associated with fatality.

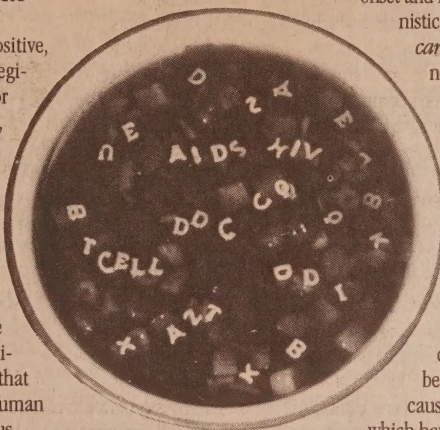
Also, HIV can develop resistance to antiretrovirals after a period of use; like the benefits themselves, this can vary from person to person. Although currently approved antiretrovirals are not a cure for AIDS, in many instances they provide improved quality of life and, possibly, prolonged survival.

Alphabet soup

Following are some of the letters you may find in your soup bowl.

AZT. As the first—and, by many standards, the most effective—antiretroviral drug, AZT remains the standard against which the effectiveness of other antiretrovirals is compared. Also known as Retrovir or zidovudine, AZT was first approved by the Food and Drug Administration (FDA) to combat HIV in 1987. The serious side effects, such as anemia and nausea, produced by the higher dosage levels prescribed at that time, are now experienced by only about 2 percent of those using the drug. Today doses of 500–600 mg daily are prescribed. Although the European Concorde study called into question the long-term value of AZT use, a range of other studies, both earlier and current, continue to point to significant quality-of-life and potential survival benefits for those taking it.

ddI. The FDA approved ddI in 1991. Also referred to as didanosine and Videx, ddI is licensed for those who cannot tolerate, who have failed to benefit from, or who have been on AZT for a prolonged time. ddI, a large, chalky tablet, must be taken on an empty stomach at least two hours after a meal and at least one half-hour prior to the next meal. The pill's large size is due to antacid buffers that may also interfere with the effects of three other drugs: tetracycline, an antibiotic; ketocon-



Muscle up

An estimated 6.5 percent of high-school boys use anabolic steroids. One quarter of them share needles. Almost 19 percent of the teenage steroid users who have had AIDS education in school have shared needles. In contrast, 30 percent of those who have had no such instruction share needles.

PATIENT ASSISTANCE HIV infection

Drug	Pharmaceutical company	Phone number
AZT (Retrovir)	Burroughs Wellcome	800-722-9294
ddI (Videx)	Bristol-Myers Squibb	800-736-0003
ddC (Hivid)	Hoffman-La Roche	800-285-4484
d4T (Zerit)	Bristol-Myers Squibb	800-842-8036
3TC	Giloxo	800-248-9757

azole (Nizoral), an antifungal; and dapsone, a PCP prophylaxis. These should be taken at least two hours before or after ddI. The recommended dosage is 250 mg twice daily.

Some studies have suggested that ddI may be at least as effective as AZT when used as a first antiretroviral therapy. The most serious side effect of ddI is pancreatitis, inflammation of the pancreas, which occurs in 5 to 9 percent of patients studied and has been fatal in a very small number of cases. Another potential side effect is peripheral neuropathy, a painful problem with nerve endings in the arms and legs; it can generally be remedied if it is detected early and ddI use is stopped.

ddC. In 1992, ddC received FDA approval, with the stipulation that it be used in combination with AZT, but only for those whose CD4 cells continue to drop below 300 despite AZT treatment. However, the FDA antiviral advisory committee has recommended that ddC be available as a monotherapy, and approval is pending.

The recommended combination dose is 0.75 mg of ddC every eight hours, along with 200 mg of AZT. The most common side effect of ddC is peripheral neuropathy, which was reported in up to 16 percent of patients and is usually reversible once ddC treatment is stopped.

d4T. Teetering on the brink of approval is stavudine, or d4T, a drug now in large clinical trials. A phase I trial found that the drug is safe and suggests an improved clinical condition, with increased CD4 counts in most patients tested. Peripheral neuropathy was discovered as a side effect when trials first began, but it subsided when dosage levels were decreased. Anemia

and liver problems have also been reported.

The drug is available free of charge from Bristol-Myers Squibb for qualifying patients. To be eligible, patients must have CD4 counts below 300 and must be unable to tolerate AZT or ddI or have declining health despite treatment with those drugs. They must also be ineligible for or unable to participate in d4T clinical trials.

3TC. An experimental drug called 3TC is currently in clinical trials at a number of sites across the country. It can also be made available through an open-label protocol to patients with CD4 cell counts under 300 who are unable to tolerate AZT, ddI, or ddC. In tests the drug, manufactured by Glaxo, has been shown to be well-tolerated with no serious toxicity. It has exhibited antiviral activity in patients ranging from asymptomatic to advanced HIV disease and AIDS.

Protease inhibitors. Compounds designed to inhibit the viral enzyme protease, required for HIV replication, are being developed by a number of companies. Abbott Laboratories' compound, known as A-80987, has been shown in test tube experiments to be active against many HIV strains encountered in patients. However, resistance may develop. Merck & Co. has created a compound, L-735,524, that is generally well-tolerated and roughly comparable in antiviral activity to AZT, although liver toxicity was noted. Contact Abbott at 708-938-3111 or Merck at 908-423-4165 for further information.

Nevirapine. Nevirapine has shown promising effectiveness against HIV. Specifically, nevirapine is a non-nucleoside reverse transcriptase inhibitor that works differently from AZT, ddI, and ddC. The drug is currently being tested alone, in combination with AZT, and in a triple combination with AZT and ddI. For further information, call Boehringer Ingelheim at 203-798-4703.

Positively Aware does not recommend specific treatments, but we do recommend that HIV-positive persons talk to a qualified physician about the range of treatment options, including antiretroviral therapies. For further information about clinical trials of the above and other drugs, call 1-800-TRIALS-A. For information on treatment issues, call Project Inform at 800-822-7422. ▲



Illustration: Dennis Regan/Body Positive

"OK! I'LL SEE YOUR TWO PROZAC ..
.. AND RAISE YOU A XANAX!"

COMBINATION THERAPY Mix 'n match

Combining more than one antiretroviral drug at a time can help some people slow the progression of HIV illness and delay development of drug-resistant HIV strains.

Although its effectiveness is not guaranteed, combination therapy has shown promise in clinical trials. Its impact can depend on a number of factors, such as an individual's previous use of antiretrovirals, her or his ability to tolerate the drugs involved, and CD4 count.

A recently completed study has noted that combining antiretroviral drug regimens is associated with elevated CD4 counts and more stable blood levels than therapy with a single agent. The trial, designed to assess the safety and efficacy of combining different levels of AZT and ddI, made it clear that combination therapies "merit further study."

Other studies have shown that combining these drugs tends to be more beneficial than alternating them. A variety of other combinations are either being studied or have been proposed.

BRIEFS

HIV-related news from media sources
 Edited by David Thomas and Scott Williams

AZT may help predict HIV disease progression

Initial responses in CD4 counts to AZT therapy predict progression of HIV disease and survival rates, according to a November 1993 *Journal of Acquired Immune Deficiency Syndromes* report. Researchers from the Multicenter AIDS Cohort Study (MACS) examined 747 HIV-infected patients who received monotherapy with AZT. Among patients whose CD4 counts were at least 400 at initiation of AZT therapy and who had CD4 increases of 50 during the first six months of treatment, AIDS-free time was prolonged 10 months and overall survival time was prolonged five months. Improvements were smaller in the rates of AIDS-free time and survival among study patients with CD4 counts below 200. Researchers also stated that a longer duration in the initial CD4 response to AZT appears to be a more important predictor of disease progression than the initial magnitude of the CD4 response.

World AIDS Day observed

"Time to Act" was the theme of the sixth annual World AIDS Day, observed on December 1, 1993. Around the world, museums marked Day Without Art by draping famous works of art with black cloth. Lights were dimmed in buildings in several U.S. cities, and celebrities and politicians headlined fund-raisers and special events and publicly commented on the epidemic. The U.S. Post Service began selling its stamp with the red ribbon of AIDS awareness. President Clinton remarked: "For nearly every American with eyes and ears open, the face of AIDS is no longer the face of a stranger." Clinton and Health and Human Services Secretary Donna Shalala outlined a new federal task force to speed drugs from the laboratory to clinical use.

The World Health Organization (WHO) estimates that 13 million men, women, and children around the world are HIV-infected, and an additional 5,000 people per day are becoming infected with HIV—3,500 per day in Africa alone. By the year 2000, WHO estimates 40 million people could be infected. Every 15 minutes in the United States, one person dies of complications due to AIDS.

Number of HIV infections estimated

The latest estimate of the number of HIV infections in the United States puts the figure at about 550,000, according to the National Center for Health Statistics (NCHS). The estimate—taken from the NCHS random sample that tested almost 8,000 people in the United States between 1988 and 1991—is much lower than the widely accepted CDC estimate of about 1 million HIV infections. However, researchers suggested that their estimate was conservative because prisoners, homeless individuals, and hospitalized patients were not included in the sample. Also, study participation by young men—a group with a high rate of HIV infection—was low, which may have further skewed results. Because of these study limitations, Dr. Geraldine McQuillan, chief author of the study, said the actual number of HIV-infected individuals in the United States may range anywhere from 299,000 to 1.02 million. The highest rate of infection was among black men ages 18–44.

French Find Second HIV Receptor: CD26

A research team at France's Pasteur Institute has isolated a co-receptor, called CD26, that works along with the known receptor CD4 in allowing HIV to invade healthy T-cells. For years, scientists have known that only CD4 cells—T-cells that exhibit the CD4 protein—can be infected, but they could not explain how the virus entered the cell. "We have found the door," said Dr. Ara Hovanessian, head of the research team. The mechanism is similar to a rod and reel: CD4 "hooks" the virus, but CD26 is needed to "reel it in." Hovanessian reported that CD4 cells which lacked CD26 were impervious to the virus. If verified, the discovery could have important implications for vaccine development and treatment research.

Field Effectiveness of HIV Vaccines Questioned

A good year for vaccine research has taken a turn for the worse. Scientists from three laboratories investigating preventive HIV vaccines announced in November that their vaccines, which seemed highly effective against lab cultures of HIV, failed to protect against strains of the virus isolated from people with HIV. The findings were announced at a vaccine meeting sponsored by the National Institute of Allergy and Infectious Diseases (NIAID) and are published in the November 12, 1993, *Science*. "This is a cause for sober reflection," said Dr. Anthony Fauci, director of NIAID. "It certainly makes me somewhat anxious." Fauci's comment and the laboratory statements have confused and troubled other vaccine developers, who have said the comment is "a huge disincentive" to begin large clinical trials of a vaccine.

New Treatment for Toxoplasmosis

Oral clindamycin and pyrimethamine are an effective treatment for toxoplasmosis, according to a report in the September 30, 1993, *New England Journal of Medicine*. An international team of investigators found that 600 mg four times a day of oral clindamycin and 75 mg a day of pyrimethamine resulted in a 71% complete or partial success rate of 49 patients in the study. Investigators also demonstrated a fast, accurate tool for identifying early toxoplasmosis, which is key to successful treatment. The potentially fatal illness, also called toxoplasmic encephalitis or toxo, is the most common neurologic disorder in people with HIV. The standard therapy of pyrimethamine and sulfadiazine provokes side effects that require discontinuation of therapy in more than 40% of cases.

House Approves Largest AIDS Appropriation

The U.S. House of Representatives voted in October to spend \$2.5 billion for AIDS programs this fiscal year, the largest yearly appropriation ever to battle HIV. In the last fiscal year, the government spent about \$2 billion on AIDS programs. This year's appropriation, approved by a 311 to 115 vote, includes \$1.3 billion for AIDS research, \$579 million for the Ryan White Emergency CARE Act (almost doubling funding of the Act, which provides for a variety of services), \$543

million for prevention and education, and \$350 million for a grab-bag of other services, including training of healthcare professionals. The Senate is expected to grant the measure final congressional approval within a month.

AIDS Eighth Cause of Death in 1992

AIDS is the eighth leading cause of death in the United States, according to preliminary statistics released by the Department of Health and Human Services (HHS). Heart disease and cancer, respectively, topped the list. The ranking of AIDS as a leading cause of death has been consistently rising over the past years, from eleventh in 1989, tenth in 1990, and ninth in 1991. The HHS preliminary number of AIDS deaths in 1992 was 33,590 people.

Anti-AIDS Laws Struck Down in Courts

A Utah law that invalidated the marriages of people with AIDS was voided by a federal judge at the request of two families and the state itself. A U.S. district judge ruled that the law, passed in 1987, violated the Americans with Disabilities Act and the Rehabilitation Act of 1973. Utah's governor and attorney general, who agreed that the law was probably invalid, offered to block its enforcement until the next legislative session, but lawyer Brian Barnard sued on behalf of two HIV-

positive women, asking for an immediate ruling in respect of his clients' health. The state asked the federal judge to invalidate the law. Even the law's sponsor agreed it should not have been passed: Asked about how much thought had gone into writing the statute, he said, "I don't think there was any."

A different federal judge struck down part of an Alabama law that allowed physicians to test patients for HIV without their permission if a patient was thought to be at risk. Testing without consent is still permissible under specific situations.

NOTICE

Opinions expressed in various articles are not necessarily those of the membership or administration of Test Positive Aware Network, Inc., Burroughs Wellcome Co., or any local distributing agencies.

Information and resources listed in *Positively Aware* are for informational purposes only and do not constitute any endorsement or recommendation by Test Positive Aware Network Inc., Burroughs Wellcome Co., or any local distributing agencies of, or for, any medical treatment or product.

TPANetwork recommends that any and all medical treatment you receive or engage in be discussed thoroughly and frankly with a competent, licensed, and fully AIDS-informed medical practitioner, preferably your personal physician.

Although great steps have been taken in an attempt to insure the accuracy of all the information presented herein, *Positively Aware*, the staff, and volunteers who produce it, TPA Network, or various institutions and personnel who provided us with information, cannot be held responsible for any damages, direct or consequential, that arise from the use of this material or due to any errors contained herein.

OFF THE WIRE....

Vitamin A and HIV. A deficiency of vitamin A may shave as much as a year off the life of people with HIV, according to a study of 126 HIV-positive injection drug users. Dr. Richard Semba of Johns Hopkins University, who led the study, said that what this finding suggests is that "there is still a great deal we don't know about optimal nutrition status for AIDS patients." Semba warned against HIV-positive people taking huge amounts of vitamin A as a result of his research. He said that no evidence suggests that extra intake of the vitamin will prolong survival and vitamin A is toxic in large amounts. Semba said the next step is to explore possible treatments based on the findings.

Good surgery results for people with HIV. Surgery poses no special threat for asymptomatic people with HIV, according to a study announced by the American Academy of Orthopaedic Surgeons (AAOS). "Many surgeons are uncertain about the advisability of surgery because of the HIV-positive patient's inherent risk of infection, poor wound healing, and perceived poor outcome," said investigator Dr. James V. Luck, Jr. of the University of Southern California School of Medicine. Luck said data show that asymptomatics "appear to have zero increase of risk" of delayed healing or infection following surgery. People with AIDS have some increased risk, he said, which can be lowered if the surgeon is aware of the AIDS diagnosis.

HIV-positive playwright denied hotel room in Japan. Alexander Martin, a Hawaiian playwright whose work "Paradise House" had a run in Tokyo, was denied accommodations at 18 hotels in the Japanese capital. His Japanese producer, Takao Okuyama, had successfully booked rooms at the hotels. "But after

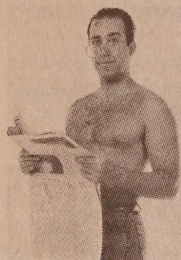
I said [Martin] is an HIV case, they rejected him," Okuyama said. In response, the Japanese government has instructed the hotel industry not to turn away people with HIV and plans to educate the industry. The incident has many HIV advocates concerned, however, because Yokohama, near Tokyo, is the site of the Tenth International AIDS Conference next August.

Comprehensive AIDS plan released: The National Institute of Allergy and Infectious Diseases (NIAID) has released the "HIV/AIDS Research Agenda," a document that presents current AIDS research tactics, knowledge gaps, and plans for future research. Dr. Anthony Fauci, director of NIAID, stated that this was the government's first attempt to document "the breadth and depth of the comprehensive NIAID AIDS research program and future plans in...AIDS research."

Magic Johnson lawsuit settled: Magic Johnson and the woman who accused him of infecting her with HIV have reached an out-of-court agreement. Johnson had admitted to one sexual encounter with the woman in June 1990, over one year before learning of his HIV-positive status. The lawsuit was dismissed on December 9, 1993, and both sides refused to comment on details of the settlement.

Body tissue regulations issued: Body tissues such as skin, bones, and corneas used in surgical transplants will now be tested for HIV and other diseases, according to the Food and Drug Administration (FDA). The new rules will also ensure that all donors and their body tissues used for transplants are tested for disease. The FDA regulations are interim, however, pending the approval of congressional legislation that would "require all organizations that supply tissue to screen donors, test tissues for the presence of disease, keep records, and submit to inspections," according to the December 11 *New York Times*. ▲

Referencias en español



Póngase en contacto con estas organizaciones para más información en español sobre VIH/SIDA.

Acción en SIDA. Un boletín internacional sobre la prevención y control de SIDA. Incluye signos y síntomas de varias enfermedades y artículos sobre SIDA en la comunidad latina. Publicado por el Colectivo Sol. Póngase en contacto con Hector Diaz, c/o Cerrada Miguel Hidalgo, No. 11 Quieto, A.P. 14040, México, D.F. Teléfono: 52-5-606-7216.

Amigos Contra El SIDA. Una revista dedicada a las personas que viven con VIH/SIDA. Publicada bimestral por la Organización Mundial de la Salud. Envíe su cheque o giro de \$28 (6 números), \$50 (12 números) a Amigos Contra El SIDA. A.C. Apdo. Postal 13-589 México, D.F. 03500, México.

El Cuerpo Positivo. Un boletín bilingüe publicado por Body Positive. Aunque la mayoría de la revista está en inglés, incluye artículos en español sobre el SIDA. \$35 contribución; gratis para personas con VIH/SIDA. Póngase en contacto con Body Positive, 2095 Broadway, Suite 306, New York, NY 10023. Teléfono: 212-721-1346.

Guía para Beneficios de Incapacidad de Seguro Social. Un folleto explicando cómo el Seguro Social puede ayudar a personas infectadas con VIH. Visite su oficina local de Seguro Social y pida el folleto "Medicare" (#05-10943).

(In)visible Women. Un video sobre latinas con SIDA que desafía el miedo que el público tiene sobre el SIDA. \$63.95. Se estrenó en 1991. 26-min documental. En español y inglés. Video Data Bank, 37

South Wabash Ave. Chicago, IL 60603. Teléfono: 312-899-5100.

Libro Sobre Derechos de PCS. AIDS Legal Rights Handbook. Póngase en contacto con NGR, 540 Castro St., San Francisco, CA 94114.

Manual Sobre Pruebas Clínicas Contra El SIDA/VIH. Un guía publicado por AmFAR (American Foundation for AIDS Research) diseñado para educar a médicos y a otros profesionales de los riesgos y beneficios de participación en pruebas clínicas y de los derechos y responsabilidades de personas que desean participar. Póngase en contacto con Centro Internacional del SIDA, U.S. Public Health Service. Teléfono: 1-800-458-5231, #1.

Mujer Imagen de Vida. Un boletín del norte de California que ayuda a mujeres compartiendo información sobre sus casos. Publicado por WORLD, Women Organized to Respond to Life-threatening Diseases. Publicado dos o cuatro veces cada año. Póngase en contacto con WORLD, P.O. Box 11535, Oakland, CA 94611. Teléfono: 510-658-6930.

Nivel de Tratamiento Básico Para el VIH. Recomendaciones básicas para el paciente que prueba positiva para el VIH. Publicado por ACT UP Philadelphia y el Proyecto Galalei. Póngase en contacto con David Acosta, 215-977-7556.

Noticias Positivas. El boletín de San Francisco AIDS Foundation publicado tres veces al año. Para saber en qué lugares se distribuye póngase en contacto con Angel García, 415-864-5855 x2092.

Pacto Latino. Un boletín en inglés y español por PACTO, un programa para latinos afectados con el VIH. El periódico se publica cuatro veces al año. Póngase en contacto con PACTO, PO Box 84027, San Diego, CA 92138. Teléfono: 619-294-6622 o 619-692-2077.

¿Qué es un Virus? Un libro para niños que explica VIH y SIDA. Por David Sasler y Kelly McQuее. Traducido del inglés. Publicado por Waterfront Books, 98 Brooks Avenue, Burlington, VT 05401. Ordénelo de Lambda Rising Bookstore, Washington, DC. 1-800-621-6969.

Quipú. Un boletín nacional de educación y información sobre VIH/SIDA. En español publicada trimestralmente. Póngase en contacto con Rhode Island Project AIDS, 95 Chestnut St., 3rd Floor, Providence, RI 02903-4161. Teléfono: 800-726-3010.

SIDAvances. Publicación del Instituto del SIDA de San Juan. Póngase en contacto con Advanced Community Health Services, Ave. Ponce de Leon, Edif. Banco de Ponce, Oficina 711, Santurce, PR, 00907. Hospital Municipal. Teléfono: 809-725-0320. ▲

SUBSCRIBE TO POSITIVELY AWARE!

Positively Aware has been publishing a Chicago edition for almost five years. They're available to you for a suggested contribution of \$25 for a one-year subscription. Subscriptions are mailed free to those with HIV who are unable to contribute.

Name: _____

Address: _____

City: _____

State, ZIP: _____

Our mailings are in plain brown envelopes. TPA's mailing list is kept completely confidential. For more information, write *Positively Aware* at 1340 West Irving Park Road, Box 259, Chicago, IL 60613.

Recommended reading

Many good sources of information about HIV/AIDS are available at little cost for a person with HIV/AIDS. We urge you to subscribe to one or more of them; call them to confirm subscription rates.

AIDS/HIV Treatment Directory. A directory published by the American Foundation for AIDS Research (AmFAR), updated quarterly. U.S. subscription, \$55.00/year. 212-682-7440.

AIDS Treatment News. Biweekly developments in research, experimental therapies, and treatment options. John James, P.O. Box 411256, San Francisco, CA 94141. 800-873-2812.

Being Alive. Monthly medical updates and information; several pages in Spanish. 3626 Sunset Blvd., Los Angeles, CA 90026. 213-667-3262.

BETA (Bulletin of Experimental Treatments for AIDS). A publication of the San Francisco AIDS Foundation, Box 426182, San Francisco, CA 94142-6182. \$55/year for individuals; \$125/year for institutions. Call 415-863-2437. To charge, call 800-959-1059.

Body Positive. Monthly magazine for HIV-positive people. A contribution of \$35/year is requested. 2095 Broadway, Ste 306, New York, NY 10023. 212-721-1346.

The Common Factor. Newsletter of the Committee of Ten Thousand, an organization by, for, and of people infected with HIV through blood and blood products. Donations gratefully accepted. * The Committee of Ten Thousand, c/o The Packard Manse, 583 Plain St., Stoughton, MA 02072. 617-344-9634.

Clinical Trials Hotline. A toll-free hotline operated by the NIH, CDC, and FDA to provide information on all HIV-related clinical trials in the U.S. Callers may request a Spanish-speaking operator. Lines are open Monday–Friday, 9:00 am–7:00 pm, EST. 1-800-TRIALS-A.

Critical Path AIDS Project. Newsletter featuring medical articles and treatment issues. Published monthly, including a listing of Philadelphia-area resources and reprints from other newsletters. Donations appreciated. * Critical Path AIDS Project, 2062 Lombard St., Philadelphia, PA 19146. 215-545-2212.

DPN: Diseased Pariah News. A humorous publication for persons with HIV/AIDS featuring sarcastic articles. DPN publishers describe their work as being “free of teddy bears, magic rocks and seronegative guilt.” Quarterly available for \$10/year. Forge of God Press, P.O. Box 30564, Oakland, CA 94604. 510-891-0455.

HIV Frontline. Monthly newsletter aimed at mental health and healthcare professionals who counsel people living with HIV. Published by NCM Publishers, Inc.,

200 Varick St., New York, NY 10014. 212-691-9100.

NAPWA Link. The National Association of People with AIDS bulletin board system. Includes multiple databases of several treatment newsletters, press clips, and information exchange. Membership varies from \$65 to \$300. 202-898-0414. BBS# 703-998-3144.

The Network. Education and information on HIV. The Network, 259 W. 30th St., New York, NY 10001. 212-268-4196. For information in Spanish, call 212-643-0870.

Notes from the Underground. Therapies, treatment strategies, “underground” treatment access. Suggested donation: \$35.* Six times a year by PWA Health Group, 150 W. 26th St., #201, New York, NY 10001. 212-255-0520.

PI. Perspective. Published by Project Inform with briefing papers issued between publications. Any donation for subscription is appreciated. 1965 Market St., Suite 220, San Francisco, CA 94103. 1-800-822-7422.

PAACNOTES. The monthly newsletter of the Physicians Association for AIDS Care. Clinician-based, but also focuses on the ethical, legal, and psychosocial aspects of the HIV epidemic. \$60/year.* 101 W. Grand Ave., #200, Chicago, IL 60610. 312-222-1326.

Positively Aware. The monthly journal of Test Positive Aware Network in Chicago. Focuses on treatment, social, personal, science, and other issues and news. \$25 donation requested for 12 issues.* 312-472-6397.

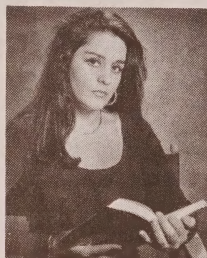
PWA Newsline. Monthly magazine written by and for people with HIV covering all aspects of living with AIDS. PWA Coalition of New York, 50 W. 17th St., 8th Floor, NYC, NY 10011. 800-828-3280.

Seasons. A newsletter of the National Native American AIDS Prevention Center. Articles and artwork by Native Americans affected by HIV/AIDS. Subscriptions are free in the U.S. American AIDS Prevention Center, 3515 Grand Ave., Suite 100, Oakland, CA 94610. 510-444-2051.

Treatment Issues. The GMHC Newsletter of Experimental AIDS Therapies. A \$30 donation is requested; available free to PWAs. Published 12 times a year. GMHC Department of Medical Information, 129 West 20 St., 2nd Floor, New York, NY 10011. 212-337-3695.

Treatment Update/Traitement Sida. The most current AIDS treatments in Canada and elsewhere. Available in French or English.* Community AIDS Treatment Information Exchange (CATIE), 517 College St., Suite 324, Toronto, Ontario, Canada, M6G 4A2. 416-944-1916.

WORLD. A newsletter for HIV-affected women. Sliding scale suggested donation. Women Organized to Respond to Life-threatening Diseases—WORLD, P.O. Box 11535, Oakland, CA 94611. 510-658-6930. ▲



Asterisk () denotes free or reduced rate for people with HIV or AIDS.*

rubbercapuchajohnsoncovergumm
 lifejacketbilletdouxprophylactic
 camisinhasl...glovesleeve
 preservatif...jimmyrain
 coatsomb...sugorrito
 pocketpalkar...rubberduckie
 barrier...eyhood
 umbrellacondomchajohnson
 covergumm...billetdouxprophy
 lacticcamisinhasl...glovesleeve
 preservatif...jimmyrain
 coatsomb...sugorritopocketpa
 kapotepreservativorubberduckiebarrie
 methodhomehoodumbrellacondomrubbe



No matter what you call it, wear it!

Adapted from a campaign of the Whitman-Walker clinic, Washington, D.C.

Sega Charitable Trust

HIV/AIDS

A Challenge To Us All



Pediatric AIDS Foundation

HIV/AIDS: A Challenge to Us All

This parent education program, geared toward the parents of elementary and pre-school children, consists of a parent meeting guide book, and two accompanying videotapes. The guide and one of the videotapes gives all necessary information so any adult can set up a parent meeting in their community. The other videotape demonstrates how parents can answer children's questions about HIV/AIDS with age-appropriate responses. The kit is available in English or Spanish and is free by contacting the:

Pediatric AIDS Foundation
1311 Colorado Avenue
Santa Monica, CA 90404
(310) 395-9501

This excellent resource could be easily adapted for use by church school classes, by conference leadership in training teachers of children, and by individuals working to develop policies for church day care and nursery facilities.

AIDS MINISTRIES NETWORK -- FOCUS PAPER

ORDER FORM

(AIDS Ministries Network Focus Papers are published by the Health and Welfare Ministries Program Department, General Board of Global Ministries, The United Methodist Church, Room 350, 475 Riverside Drive, NY, NY 10115. Direct inquires and request to Reverend Charles Carnahan, Executive for HIV/AIDS Ministries at the above address or by phone 212-870-3909, fax 212-870-3873.)

If you would like to receive previous Focus Papers, please indicate your choice with a check mark. Return this form to the address above.

FOCUS PAPER TITLES

- | | |
|--|---|
| ☐ #2: God's Love We Deliver: Home Delivered Food Service | ☐ #14: The Epidemic of HIV Infection in the United States |
| ☐ #3: AIDS Ministries and The United Methodist Church | ☐ #15: The Global AIDS Pandemic: Facts and Figures |
| ☐ #4: Living with AIDS: A Personal Journey | ☐ #16: Binding Up the Brokenhearted Children |
| ☐ #5: AIDS Bibliography: Selected Resources for Church Educators | ☐ #17: Women Don't Get AIDS: They Just Die From It (Part I) |
| ☐ #6: AIDS: A Covenant to Care | ☐ #18: Women Don't Get AIDS: They Just Die From It (Part II) |
| ☐ #7: Spiritual Life Retreats Enrich AID Ministries | ☐ #19: The Healing Ministry of the Church in the Second Decade of AIDS |
| ☐ #8: This Is The Day (A Care Provider's Story) | ☐ #20: Have I Died Already or Am I Still Alive |
| ☐ #9: AIDS Information and Resources To Meet Your Needs | ☐ #21: IXth International HIV/AIDS Conference: Highlights |
| ☐ #10: Threads of Love: A Tapestry of Remembrance (The NAMES Project AIDS Memorial Quilt) | ☐ #22: Pastoral Care and HIV/AIDS Ministry |
| ☐ #11: Children and HIV Infection | |
| ☐ #12: Basic Information on AIDS/HIV Infection and Related Illnesses | |
| ☐ #13: AIDS and the Power of God's Goodness and Grace | |

Name: _____

Address: _____

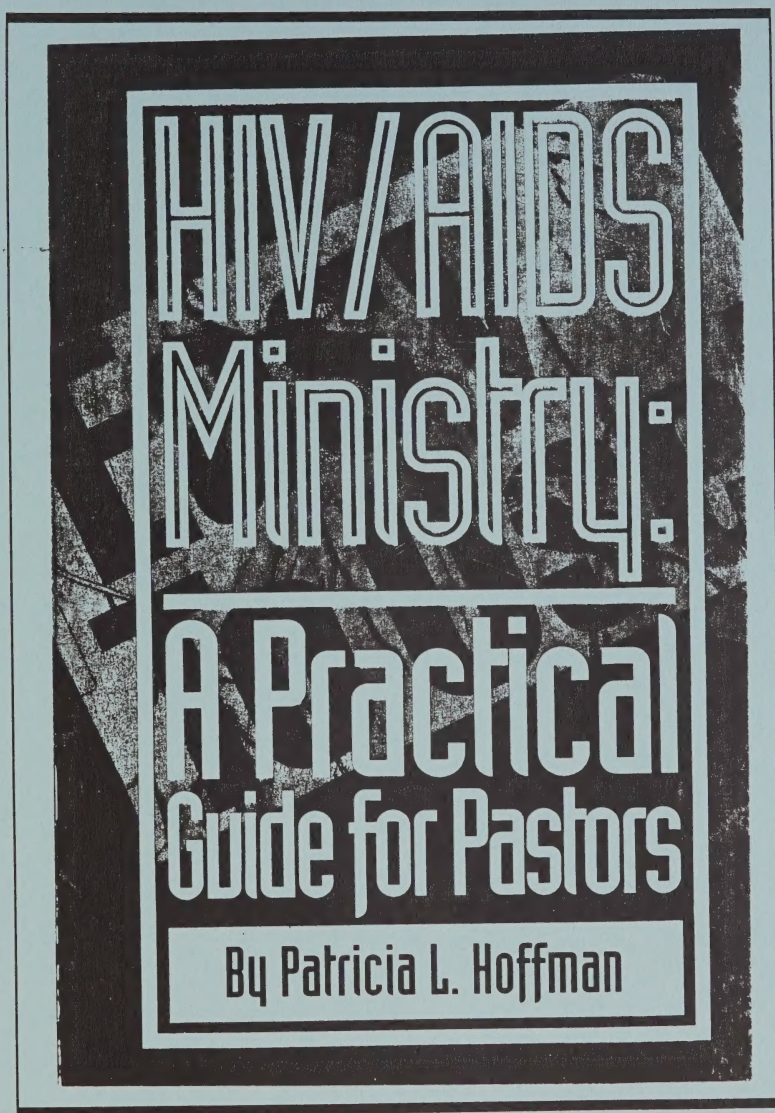
City/State: _____

Zip: _____

**A
NEW
HIV/AIDS**

**M
I
N
I
S
T
R
Y

R
E
S
O
U
R
C
E**



*HIV/AIDS Ministry: A Practical Guide for Pastors
by Patricia Hoffman*

This new resource provides pastors, lay church professionals, and church leaders with practical, straight forward information on how to deal with the issue of HIV/AIDS from a compassionate basis. True stories of individual and congregational struggles with HIV/AIDS provide valuable insights to responding to the needs of persons living with HIV disease. Practical models of response will enable any congregation to develop its own compassionate response. Order item #1839, from Service Center, 7820 Reading Road, Caller No. 1800, Cincinnati, Ohio, 45222-1800. Price \$5.95 plus \$1.50 shipping.

Recommended for every pastor's, church's, and individual's resource library!

HIV / AIDS MINISTRIES NETWORK

FOCUS PAPER # 22

A NETWORK OF UNITED METHODISTS AND OTHERS WHO
CARE ABOUT THE GLOBAL HIV/AIDS PANDEMIC AND
THOSE WHOSE LIVES HAVE BEEN TOUCHED

ABOUT THIS ISSUE
November 1993

IN FOCUS PAPER # 22

About This Issue cover

"GUIDELINES FOR THE
GIVING OF PASTORAL CARE
TO THOSE INFECTED/
AFFECTED BY HIV/AIDS" 1
by Don Nations

"10 ASSURANCES OF
PASTORAL CARE FOR THOSE
INFECTED OR AFFECTED BY
HIV/AIDS" 5
by Don Nations

"DO UNTO OTHERS..." 12
by Richard Cory

"PASTORAL CARE: A
PATIENT'S PERSPECTIVE" 17
by William Nunn

Dear Network Members:

One question we are most frequently asked is *"How do I talk to or counsel with a person living with HIV disease?"* This question is not only asked by care partners, friends, and family but also by church professionals, clergy and lay. Even though most religious professionals have had to take some course(s) in pastoral counseling, they often feel inadequate when it comes to providing emotional/spiritual support to individuals and families affected by HIV disease.

This edition of the HIV/AIDS Ministries Network Focus Paper is devoted to providing some insights and practical assistance to anyone faced with responding to the emotional/spiritual needs of persons living with HIV/AIDS.

HIV/AIDS Ministries Network Focus Papers are a publication of the Health and Welfare Ministries Program Department, General Board of Global Ministries, The United Methodist Church, Room 350, 475 Riverside Drive, New York, NY 10115. Phone: 212-870-3909. FAX: 212-870-3873. Focus Papers, unless otherwise noted, may be quoted, reproduced and distributed with credit being given to Health and Welfare Ministries Program Department and the authors.

The emotional/spiritual needs of persons living with HIV disease have never been more acute. HIV infected individuals are living longer than any time in the past 12 years. Because they are living longer, they have to deal with longer-term stresses. Increasing numbers of family members and significant others are choosing to care for the infected individual and also needing emotional/spiritual support themselves. More and more church and community members are coming out of the closet to let it be known that they or their loved one has HIV disease. Increasingly they are seeking out and even demanding supportive, compassionate, and non-judgemental emotional/spiritual support from our religious communities.

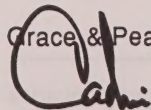
In "*Guidelines for the Giving of Pastoral Care to Those Infected/Affected by HIV/AIDS*" and "*10 Assurances of Pastoral Care for Those Infected or Affected by HIV/AIDS*," the Reverend Don Nations provides the theological and psychological framework out of which appropriate emotional/spiritual support needs to take place. My own experience supports the notion that such a framework most adequately addresses the emotional/spiritual needs of persons infected with or affected by HIV disease.

However, read closely (and if necessary often) the reflections of Richard Cory and William Nunn in the **U.M.C. Family HIV/AIDS Network** concerning the pastoral care they experienced first hand (both appropriate and inappropriate emotional/spiritual support). They indicate clearly what they found helpful and harmful. All of us who find ourselves or choose to be care partners with persons living with HIV infection will do well to open ourselves to hear the voice of the Creator spoken through these two stories of faith.

In your Focus Paper mailing, you will find information and/or order forms for a number of new resources. One resource I would invite you to secure is the book recently published by the Department, *HIV/AIDS Ministries: A Practical Guide for Pastors* by Pat Hoffman. The Department believes it is a basic HIV/AIDS ministry resource which every clergy, lay church professional, or anyone seeking to be in ministry with persons living with HIV disease will find helpful.

If you have not done so, we invite you to join the hundreds of individuals working with and living with HIV disease who are finding support and resources through the **Computerized AIDS Ministries Resource Network**. A flyer at the end of this Focus Paper gives you the details on how to sign-up.

Grace & Peace,



Cathie Lyons
Associate General Secretary

Charles Carnahan
Executive for HIV/AIDS Ministries

GUIDELINES FOR THE GIVING OF PASTORAL CARE TO THOSE PERSONS WHO ARE INFECTED/AFFECTED BY HIV/AIDS

by Don Nations

1. THE FIRST QUESTION TO ASK IS NOT, "HOW DID YOU GET INFECTED?"

We do not ask someone who has cancer, lupus, or suffered a heart attack how they got sick; so why should we ask that of someone with HIV? When someone tells us their HIV status, they are usually dealing with the present and future more than the past. There may be lifestyle issues that need to be discussed at a future time, but our initial reaction needs to be compassion-- not questioning.

2. AVOID THE 'BLAME GAME.'

Spending time blaming people who are HIV positive for their illness distracts from the most important issues. The truth is that we have all done things in our life that involved risk. For the most part, we have been spared the consequences of those acts. We are hypocritical when we blame others if they suffer the consequences of their acts. The "blame game" prevents us from giving beneficial pastoral care to those who need it.

Compassion is being a channel of God's grace and coming to the side of one who is hurting.

3. COMPASSION IS THE KEY.

Compassion is being a channel of God's grace and coming to the side of one who is hurting. We suspend judgmentalism and focus on the needs of others. Compassion is shown in gentleness, kindness, acceptance, and love. Pastoral care that lacks

compassion is not helpful. Compassion is the way of Jesus.

4. CONFRONT YOUR OWN FEARS.

Fear leads some pastors and churches to reject people infected/affected by HIV/AIDS. They may refuse to visit or care for them. We must confront our fears with facts, put judgmentalism and prejudice behind us, and get on with the privilege and obligation of ministry.

5. FOCUS ON LIFE, NOT DEATH.

A person infected with HIV will eventually die. So will a person who is not infected by HIV. We all will die; none

of us knows when death will arrive. Therefore, our focus needs to be on how we will live the rest of our life. Focusing only on death gives the impression that we have given up hope and are just waiting for the person to die. Focusing on life declares that the person has a lot of living yet to do.

6. LET THE INDIVIDUAL SET THE AGENDA.

Many of us like to be in control of everything, including the direction of our conversations. This approach can sabotage our best efforts. The earlier you are in your relationship with the person you are

counseling the more they need to control the issues that are discussed. If you begin a relationship by making demands of the HIV positive person such as his/her immediate repentance, notification of family/partner(s), and acceptance of death, you are being, at best, unfair and unhelpful. At worst, you are being destructive.

7. CONFIDENTIALITY IS A MUST.

We must keep the trust people place in us. Disclosing one's HIV status is often a difficult decision. It means becoming vulnerable and trusting another with a secret. Pastoral visitors are not free to tell others secrets entrusted to us. We do not tell spouses, church committees, pastors, or friends. If we break confidentiality, we may hurt the one who trusted us so much that he/she never reaches out for help again.

8. ACT LIKE THERE IS HOPE.

HIV infection is not a situation completely devoid of hope. New medications are extending the lives of persons infected with HIV. A cure may be found. There is the power of prayer. Most importantly, we all have much living left to do. The gospel of Jesus Christ is a call to hope that this life is meaningful because God is working in our life and eternity will be spent in the presence of God.

...our focus needs to be on how we will live the rest of our life. Focusing on life declares that the person has a lot of living yet to do.

9. AFFIRM THE WORTH OF THE PERSON.

All people are created in the image of God. All people inherently have great dignity and eternal worth. God's grace has gone out to all

people and God, calling all people to a life filled with power, love, joy, and service to others. "God so loved the world" (John 3:16) means that there are no second class people. We must embody the message of love or we fail to offer the Gospel.

10. FEEL FREE TO SHOW EMOTION.

HIV/AIDS surfaces concerns about death, prolonged illness, lack of control of our lives, financial stability, transmission of the disease, prejudice, and more. The giving of good pastoral care requires that we confront these issues and get in touch with our own emotions about them. We must be careful, however, to respond to the needs of the person and not our own anxiety, fear, and pity. Our role is to be a pastor to them, not the reverse. Be emotionally present. Feel free to appropriately cry, laugh, or express other emotions when visiting with a person who has HIV.

11. REMEMBER TO TOUCH.

One of the tragedies of HIV infection is that many people are reluctant to touch someone who is HIV positive. Some of this hesitation is due to irrational fears about contracting HIV through casual contact. Others hesitate because they do not accept the HIV positive person or the lifestyle they are believed to have. Whatever the reason, refusing to touch someone who wants to be touched sends the message that we are not emotionally present for the person or that we do not accept the person. (We must also be sensitive to times when a person does not want to be touched for any reason or cannot be touched because of a physical condition.)

Our willingness to touch shows our willingness to care.

12. LOOK FOR THE STAGES OF GRIEF.

People who are infected/affected by HIV wrestle with the stages of grief. They deal with shock, denial, anger, bargaining, depression, and acceptance. People go through these stages in differing periods of time and may bounce back and forth between stages. People will grieve over their HIV status, an AIDS diagnosis, the loss of a job, becoming symptomatic, the loss of their future, the death of their friends, and the anticipation of their own death. Our job is not necessarily to move people through these stages but to help them deal with their present stage. We are called to offer support to our brothers and sisters during these difficult times.

**CONFIDENTIALITY
IS A MUST.**

13. BE AWARE OF THE PSYCHOSOCIAL ISSUES SURROUNDING HIV/AIDS.

Those infected/affected with HIV deal with a variety of issues such as social isolation, rejection by friends and family, prolonged periods of illness, fear of what tomorrow will bring, the sometimes negative reactions of the religious community, reproductive decisions, guilt, and grieving. As givers of pastoral care, we need to recognize these issues and help people as they work their way through them. We also need to educate our community about HIV/AIDS so that it may respond supportively.

14. EXPRESSIONS OF SPIRITUALITY AND THE EXPERIENCE OF SPIRITUAL LIFE VARIES FROM PERSON TO PERSON.

No one experiences God in the same way. Some people express their faith emotionally; others are quiet and contemplative. Some people enjoy singing; others prefer to listen. Some belong to a particular religious group; others do not. Some are very sure about their spiritual direction; others are searching and have a lot of questions. Such differences are not bad. They demonstrate the unique way God reaches out to all of us.

Since religious expressions differ, we must not require everyone to experience God the way that we do. We can not assume that we know another person's spirituality just because we know they are infected/affected by HIV. We must be present as pastoral guides who help people to find their own way on their spiritual journey.

15. AVOID SAYING, 'I KNOW HOW YOU FEEL.'

Even if we had similar situations, we cannot completely understand how anyone else is experiencing a particular situation. More helpful responses include, "I hear your pain"; "I am sorry"; "I am here for you"; "I understand this is a difficult time for you"; "What can I do to help?"; and "How do you feel?" Sometimes a quiet hug is appropriate and needed.

16. GET EDUCATED.

To give helpful, consistent pastoral care, educate yourself about HIV infection. Learn the basic facts about modes of transmission,

progression of the infection, common illnesses and medications, and the psychosocial issues that surround HIV/AIDS. Becoming educated about HIV communicates to people with HIV that you care about them. You can find out about HIV in many ways: books, tapes, seminars, volunteer opportunities, HIV/AIDS hotlines, American Red Cross programs, denominational resources, hospitals, and more. However you choose to become educated, do it today.

17. PASTORAL CARE WITH A PERSON INFECTED/AFFECTED BY HIV/AIDS IS USUALLY A LONG PROCESS.

We cannot heal every wound and solve every problem in one hour. Pastoral care with someone whose life has been touched by HIV requires time, patience, and the development of a relationship. Our role is to come along side of people and support them, to be present with them. It is not to answer every question and give the solution to every problem. We must be patient as people work through the stages of grief and the myriad of issues that surround HIV infection.

18. KNOW YOUR LIMITS.

HIV brings us into contact with issues such as counseling, bio-ethics, living wills, medical treatment, grief, guilt, stress reduction, and nutrition. None of us can adequately deal with all of these issues. We must realize when we have reached our limits and be willing to refer the client to another person.

19. EVERY PASTORAL CARE SITUATION CAN BE USED BY GOD TO MAKE US INTO THE PEOPLE GOD WANTS US TO BE.

God meets us in the people we encounter. People living with HIV, through the issues they raise, help us confront fear, death, frustration, impatience, prejudice, and spirituality. Walking through these issues with our them can be mutually beneficial. We must always be open to growth and personal change.

20. DOCTRINE, DOGMA, DENOMINATIONALISM, AND GUIDELINES ARE NOT ADEQUATE SUBSTITUTES FOR CARING, SHARING, AND LOVE.

We all operate within the structure of a religious organization. That does not mean, however, that all we have to offer is that structure. We must add to that framework caring, personal sharing, and love. Unless we become personally involved, we will fail to show God's love to others and fail to follow the example of Jesus.

10 ASSURANCES OF PASTORAL CARE FOR THOSE INFECTED OR AFFECTED BY HIV/AIDS

by Don Nations

Assurance #1

GOD LOVES ALL OF US.

Scripture: John 3:16-18; John 10:27-29; Romans 8:35-39; 1 John 4:7, 8

God is love. God's love is extended to all people. It has no end and is unconditional. God's love has no "ifs, ands, or buts." No one and no thing can separate us from the love of God that is in Jesus.

We are all precious to God. Jesus lived, died, and was raised from the dead in order to demonstrate God's love for us. Our love for God is demonstrated by our loyalty to Jesus and our love for one another.

Even when we feel unloved or unlovable, God's love is constant. Even when we disappoint ourselves, God continues to love us. Even when others turn their love away from us, God's love for us never waivers.

HIV infection often makes us feel separated from others-- our families, our friends, our partner, even God. The Scriptures assure us that nothing can separate us from God's love-- not even HIV. In the midst of the challenges of HIV/AIDS, we can be assured that God still loves us.

God accepts us right where we are. That does not mean that God approves of all we do or that God is willing to leave us just the way we are. It does mean that God's acceptance is unconditional. We are loved!

10 Assurances of Pastoral Care For Those Infected or Affected by HIV/AIDS

- 1. GOD LOVES ALL OF US.**
- 2. GOD WILL DRAW NEAR TO US.**
- 3. GOD OFFERS FORGIVENESS.**
- 4. GOD IS WITH US.**
- 5. GOD BRINGS GOOD INTO OUR LIFE.**
- 6. GOD GIVES US A PURPOSE.**
- 7. GOD GIVES US STRENGTH**
- 8. GOD'S GIFTS ARE PEACE, HOPE, AND JOY.**
- 9. GOD TAKES THE SIDE OF THE POOR, THE SICK, AND THE OPPRESSED.**
- 10. GOD NEVER GIVES UP ON US.**

Assurance #2

GOD WILL DRAW NEAR TO US.

Scripture: Psalm 145:18; Ephesians 2:13-14, 19; Hebrews 10:19-22; James 4:7, 8

An affliction far more common than AIDS is "FRAIDS," an irrational fear of HIV/AIDS and those infected/affected by HIV. This fear produces anger, discrimination, spreading of myths, and avoidance of those infected/affected by HIV/AIDS.

God does not have 'FRAIDS! God desires intimate contact with us. God wants to hear our concerns, fears, hopes, dreams, and questions. God wants to cry with us and laugh with us. God wants to hear our prayers and to talk with us.

When HIV touches our life, we often experience the end of some relationships. Because we do not want to be hurt again, we can become reluctant to reach out to others.

The Scriptures assure us that nothing can separate us from God's love-- not even HIV. In the midst of the challenges of HIV/AIDS, we can be assured that God still loves us.

God wants us to take the chance and reach out. God will never hurt us. God will never turn away from us. God will not cut off our spiritual relationship with Jesus Christ. We can be sure that if we reach out to God, we will find that God is already reaching out to us. If we draw near to God, God will draw near to us (James 4:8).

Assurance #3

GOD OFFERS FORGIVENESS.

Scripture: Psalm 130:1-4; Isaiah 1:18-19; I John 1:9-2:2

Guilt! We have all felt it. We have carried it around with us. We have been its victim. The good news is that God has provided a way for us to unload our burden of guilt. That way is God's forgiveness of our sins through Jesus.

God's grace and forgiveness is greater than our sin. Forgiveness is God's work. Receiving God's forgiveness allows us to forgive ourselves for the mistakes we have made. It also allows us to forgive those who have hurt us.

Letting go of guilt is a healthy choice. It frees up emotional energy for us to deal with the other issues of life. It liberates spiritual energy so that we can continue our spiritual journey. It releases physical energy so that we can keep our bodies healthier.

Forgiveness also helps each of us to be honest with ourself. We must admit that we are not perfect and that some things in our life must change. This admission helps us to stop wasting time. Then we can spend our time more constructively, doing the things that make us stronger.

Forgiveness is a gift that truly is good for us.

Assurance #4

GOD IS WITH US.

Scripture: Joshua 1:5; Psalm 23; Matthew 28:18-20; Hebrews 13:5, 6; II Corinthians 4:7-10

When we are HIV positive, we can feel very isolated and alone. We need to know that someone will be there for us, even in the hard times of life. God will never desert us or leave us alone.

Many things can make us feel isolated and alone. HIV/AIDS scares some people away from us. Sometimes HIV scares us away from other people. Managing our health, visiting doctors, and dealing with changing working conditions steals much of our time, thus often preventing us from spending time with others.

God is with us, in good times or bad; in health or sickness; in strength or weakness. We may have to endure many things in this life, but we do not have to be lonely. God has promised to remain with us forever and ever-- in this life and in the next. We are not alone.

Letting go of guilt is a healthy choice. It frees up emotional energy for us to deal with the other issues of life. It liberates spiritual energy so that we can continue our spiritual journey. It releases physical energy so that we can keep our bodies healthier.

Assurance #5

GOD BRINGS GOOD INTO OUR LIFE.

Scripture: Romans 8:28; James 1:2-4, 12, 17; I Peter 1:3-9

God does not make bad things happen to us. God does not make us sick. God brings good into our life.

Bad things happen for a variety of reasons. We suffer because of the mistakes of others. We suffer because our decisions have brought negative consequences. We suffer because of the evil structures of society. Sometimes there is no satisfactory reason for our suffering.

God promises to help us bring good results out of difficult situations. HIV has affected our lives. The question we must answer is, "How are we going to react to this reality of life?"

We can choose to live in denial or face our mortality and be freed from the fear of death. We can choose to withdraw into ourselves or reach out to find the support we need and offer support to others. We can choose to run from God or to reach out and have a relationship with a God who offers us goodness, love, and care.

Assurance #6

GOD GIVES US A PURPOSE.

*Scripture: Matthew 28:18-20; Mark 1:14-20;
John 14:1-15; II Peter 1:1-8*

***God does not make bad things
happen to us. God does not
make us sick.***

One of the most terrible things is to live without purpose: to have no plans, no direction, no goals, no reason for living. To merely "exist" is a tragic way to spend our time when we could be living.

When HIV touches our life, we may feel hopeless and want to stop living. We start to lose sight of our dreams and plans. We begin to believe that we have no purpose. That is not true!

God affirms that we always have a purpose. As long as we are seeking to become better people, reach out to others, work on our spiritual growth, care and pray-- we have a purpose.

How do we find our purpose? We can start by doing a self-inventory. We can ask: "What are my talents, resources, goals, hopes, and dreams? What is most important to me? How has God gifted me?" Next, we ask: "What are the needs of my family, friends, society? What would God have me do about these needs?" Then, we ask: "Where does my self-inventory match up with the needs I see?" The intersection of our self-inventory and the needs of others may be a good place to begin fulfilling our purpose.

God offers us life. God will give us a purpose. Let us be done with existing and get on with living!

Assurance #7

GOD GIVES US STRENGTH.

Scripture: Psalm 34:4; II Corinthians 12:9, 10; Philippians 4:13

All of us feel tired and overburdened sometimes. Demands related to friends, family, work, health can tire us out. Add the challenges of HIV to this mix and it is easy for us to reach the point of exhaustion. We may begin to believe that we can not overcome the next difficulty we face.

We find strength as we become connected to God through Jesus Christ. In this spiritual relationship, we find what we can not find in ourselves. Our strength is not found in wrestling with life but in resting in God's hands (Isaiah 40:29-31).

How reassuring to know that spiritual strength is promised to those who wait upon God. How empowering to realize that we can face all challenges backed by the power of God.

Strength is not measured in weight, muscle size, or athletic ability. Strength is measured by our oneness with God. As our spiritual relationship becomes stronger, we become stronger people. God's strength will never fail us.

Assurance #8

PEACE, HOPE, AND JOY ARE GOD'S GIFTS.

Scripture: John 14:27; Romans 5:1-5; II Corinthians 12:9, 10; Philippians 4:4-7; Hebrews 4:16

Beyond the materialism and selfishness of society (and ourselves), we need peace, hope, and joy. We feel these needs more intensely when our lives are touched by HIV.

That we live in a disturbed world is not news to anyone. That we can find peace in the midst of it IS news. God offers us peace. We can have peace because we know we are God's. We know that justice will prevail. God never leaves us.

Hope and HIV are not opposites. HIV affects the body but hope is found in the soul. We hope for a cure. We hope that we can fulfill our dreams. We the have hope that after we take the step of death, our story will not end. In fact, our hope says that our existence is eternal and that one day we will be in a place with no death, illness, or tears of pain.

Hope and HIV are not opposites. HIV affects the body but hope is found in the soul. We hope for a cure. We hope that we can fulfill our dreams.

Scripture calls us to rejoice at all times. While we do not rejoice about the negative things in our life, we do rejoice that God goes through these things with us. We rejoice that the love in our hearts will last forever. We find joy in the faces of children, in the little things of life, and in the

kindness of loved ones. Without peace, hope, and love, life is unbearable. With them, we can live and thrive.

Assurance #9

GOD TAKES THE SIDE OF THE POOR, THE SICK, AND THE OPPRESSED.

Scripture: Amos 5:10-15, 21-24; Matthew 5:1-12; James 1:27; 2:2-9

God's love is extended to all people. God has a special concern for the persons who are poor, sick, and oppressed. Repeatedly Scripture defines true religion as caring for the poor, the stranger, and the afflicted. Scripture condemns the actions of those who are unjust, abuse their positions of power, and close their eyes to the needs of others.

HIV disease increases poverty. Those who are poor become poorer. Many who have been financially comfortable become poor. Due to peoples' fears and unjust social structures, being infected/affected by HIV often results in our oppression.

God does not desire us to be in poverty, to be sick, or to be oppressed, but sometimes we are. God is not indifferent to our situation. God is our advocate, our comforter, and our refuge. God's will is for justice for all. As The Reverend Dr. Martin Luther King, Jr. said, "even though the arc of the moral universe is long, it bends towards justice." The struggle may be long, but we do not struggle alone. God struggles along side of us and on our behalf.

We can take comfort in the knowledge that our situation is not forgotten by God. Jesus came to preach good news to the poor and set free the downtrodden.

God's love is extended to all people. God has a special concern for the persons who are poor, sick, and oppressed. Repeatedly Scripture defines true religion as caring for the poor, the stranger, and the afflicted.

Assurance #10

GOD NEVER
GIVES UP ON US.

Scripture: Psalm 12; Psalm 18; Proverbs 3; Hebrews 12:1-3

People sometimes break their promises, destroying our faith in them. We may become so disappointed in the actions of others that we begin to give up on people. When the people who hurt us are members of the religious community, we are tempted to give up on religious institutions and people. We can even be tempted to give up on God.

Some clergy and congregations fail to meet the needs of people. However, millions of people, including those whose lives have been touched by HIV/AIDS, have found parts of the Christian community to be very supportive.

We all need spiritual moorings, to feel connected to something greater than ourselves. We all need to feel like we have a place in eternity. We want to experience love, peace, forgiveness, and hope. We lose all of these benefits if we react to the uncaring acts of others by shutting down our spiritual life.

People will sometimes fail us, but God will not. God is always greater than the people who claim God's name. Even if we have given up on people, we do not need to give up on God. God never gives up on us.

The Reverend Don Nations is pastor of Port Tampa United Methodist Church in Tampa, Florida and a member of Florida Annual Conference. He is on the clergy advisory committee of Francis House, a spiritual outreach to those infected/affected by HIV/AIDS, and an HIV/AIDS instructor. Copies of the brochures *10 Assurances* and *Guidelines for Giving of Pastoral Care to Those Persons Who Are Infected/Affected by HIV/AIDS*, from which the two articles in this Focus Paper were adapted, may be obtained from The Reverend Don Nations, Port Tampa United Methodist Church, 6914 South DeSoto Street, Tampa, Florida, 33616, (813) 837-5002.

U.M. FAMILY HIV/AIDS NETWORK

A NETWORK OF UNITED METHODIST FAMILIES AND
OTHERS WHO HAVE BEEN TOUCHED BY HIV/AIDS

"Do Unto Others..."

by Richard B. Cory

Introduction

On 21 February 1986, Catherine and Richard Cory were blessed by the birth of Alexander Nicholas Cory, a beautiful baby boy. Afterward, Catherine experienced post-operative bleeding. She received a massive transfusion--18 units of whole blood and 4 units of blood clotting factors. (50 donors or more are required to produce 1 unit of blood clotting factors.) Catherine became comatose and spent several days in intensive care. During her recovery, she breast fed Alex.

In the spring of 1987, Catherine went to the American Red Cross to donate blood. A week or so later, the Red Cross called Catherine and asked her to come back into their office. They gave no further explanation. When Catherine went to see them, they told her that she had tested positive for HIV. Subsequent testing of the rest of the family showed that Alex was also positive and I was negative.

A general sense of well being, not only physical, but also spiritual and emotional, plays a major role in the care of persons with

life-threatening illnesses. Both medical research and personal testimonies have confirmed this. When persons are faced with their own mortality, especially at an early age, it is not uncommon for them to look to the community and especially the church for support.

Unfortunately, HIV/AIDS carries a strong stigma. Many people believe that those infected with HIV somehow did something to "DESERVE" AIDS. Despite several years of publicity and education, many only know that HIV/AIDS kills, so they want nothing to do with persons who are HIV positive. Many people still react negatively towards a friend or even family member who lets it be known that they are infected.

The result is that many who are HIV positive feel compelled to live in secrecy. As if facing a life-threatening illness is not hard enough, they have to

hide to avoid being the target of unfounded fear, hate, and bigotry born of ignorance. In short, at a time when the support of the community is most needed, it is not available. Rather than being supported, people living with HIV/AIDS often become outcasts.

Despite several years of publicity and education, many only know that HIV/AIDS kills, so they want nothing to do with persons who are HIV positive. Many people still react negatively towards a friend or even family member who lets it be known that they are infected. The result is that many who are HIV positive feel compelled to live in secrecy.

Examples of Lack of Support and Ignorance

What follows, are some experiences that I have had concerning how the lack of support and ignorance of others has affected my family.

1. When Alex was about two years old, my wife and I were both working. We enrolled him in a day care facility near home. As recommended by my son's physician, we discussed his HIV status with the owners of the day care facility. After consulting with the state health department, the Red Cross, and talking to my son's doctor, they said they would have no problem accepting him for day care.

A few months later, Cathie picked Alex up early and said something about taking him to see a doctor. A day care staff person asked about his health (presumably showing genuine concern). Alex was asymptomatic at the time. My wife spilled the beans, saying he was being treated for HIV.

During the next several days, the employee resigned her job and called the parents of other children. She told them that their children could have AIDS because they were exposed to a child with AIDS in the day care center. Many parents were very upset, even threatening a law suit. We were told that one of the loudest voices in the crowd was a medical doctor!

We had to withdraw Alex from the day care center and find other accommodations.

2. When Alex was about four, both Cathie and I were still working. A neighbor who was a very dear friend took care of Alex for us while we were at work. Alex even referred to her as his "other mommy." She was well aware of Alex's diagnosis and treated him as if he was one of her own.

The neighbor had a daughter who was just one day older than Alex. She enrolled her daughter in a preschool at a nearby Lutheran Church.

We thought this was a good idea; so we enrolled Alex as well. Cathie talked to a school administrator about Alex's condition

(still asymptomatic), who gave us a very positive response.

A couple of weeks before the school was to begin, the pastor of the church asked to come to our home to speak with us. We assumed that since we were not members of his congregation he simply wanted to meet us. When he arrived he explained that the school staff had been informed that a child would be coming that was HIV infected. They promptly offered their mass resignation if that child was admitted. He asked us to withdraw Alex. The basic idea was, if my son came to the school, there wouldn't be any school to come to. We withdrew him.

We had already told Alex that he would be going to school. He had been very proud that he was so "grown up." Now we had to tell

A couple of weeks before the school was to begin, the pastor of the church asked to come to our home to speak with us. We assumed that since we were not members of his congregation he simply wanted to meet us. When he arrived he explained that the school staff had been informed that a child would be coming that was HIV infected. They promptly offered their mass resignation if that child was admitted. He asked us to withdraw Alex.

him he could not go. It made it no easier that his best friend would be going and he couldn't. In all fairness, the pastor did invite us to attend his church and promised his support at church. The teachers in the school were not members of his congregation so he said had little influence over them.

3. When Alex was to begin kindergarten, my wife, being Catholic, wanted to enroll him in the local Catholic school. Alex was still asymptomatic but he was taking medications that would have to be dispensed during the school day.

We considered (based on our previous experiences) not saying anything to the school administration. We decided that it would only be a matter of time before someone realized that Retrovir and AZT were the same drug and the only reason for a person to take AZT is for HIV infection.

We went in and talked to the principal. Much to our dismay, the principal was dead set against him attending "HER" school.

Initially she claimed that she didn't have the necessary medical facilities. We told her that the only thing she needed was a teaspoon and a responsible adult to give him his medicine once during the school day. Then she indicated she had cancer and her immune system was depressed so she might

get "IT." We offered our sympathy and pointed out that HIV is not spread through casual contact. Ultimately, the bottom line was that she feared that if the other parents found out, she might lose enrollment. Those enrollment figures were more important than my son.

We asked the parish priest to intervene on our behalf. He told us that the school was independent of the parish and that he had no say. I asked him if he was the spiritual leader/advisor for the school. He answered

yes, but told us this was a business matter that he had no say in.

Though we have experienced hatred and bigotry, we have also received a great deal of support and friendship from many people. I remember as a child learning about Jesus ministering to the sick and lame... even to the lepers who were outcasts of society.

People with AIDS are humans too. Like everyone else they have a need to be needed... to fit in. People ask me, "What can I do to help?" I tell them that the most important thing they can do is to be a friend. That may mean just going through life as usual, providing a shoulder to cry on, maybe a comforting hug, or maybe just simply being there. Treating those with HIV/AIDS with kindness and dignity is by far the greatest gift that can be given. The "Golden Rule" applies, "Do unto others as you would have them do unto you."

We pursued the issue further.

Finally the diocese agreed to discuss it. We offered brochures from the Red Cross and speakers, including our son's doctor. They told us none of this was necessary--they would handle it.

We asked to address the meeting of the diocese; they said this was impossible. After several months, the diocese had their meeting. They decided they did not have enough information, so they postponed setting any policy until a future meeting. In the meantime, school started.

We have never heard anything further from the church concerning this. One of the most tragic losses was not only that my son could not attend the school but my wife has stopped

attending church. She feels betrayed by the church that she was raised in from an infant.

Not all of the news is bad. Following are some more upbeat stories of support and understanding.

Examples of Support and Understanding

1. Recently we told Alex that he has AIDS. He's 7 1/2 now. We had avoided telling him before. When he asked me directly, "Daddy... do I have AIDS?" I couldn't see not telling him the truth.

About a week after this conversation, Alex announced to the children at the bus stop (and several parents) that he had AIDS. A number of parents have since offered their sympathy and support. One parent reacted with anger over not being told sooner. She was afraid because her son plays with Alex frequently.

We shared the facts about AIDS with her, including brochures from the Red Cross. Then she called the National AIDS Hotline. She has turned out to be very loving and understanding, and her son still plays with mine.

2. My son wanted to join the Cub Scouts. I was concerned about the reaction that we would get when he told people, which was bound to happen sooner or later.

I called the executive director of the local council of the Boy Scouts of America. I told him of my son's condition and offered my services as an educator. (I'm a recently certified HIV/AIDS instructor.) Much to my dismay, he said there really wasn't a problem here with HIV/AIDS. He didn't see the need and had no desire for the services I could provide. Furthermore, the Boy Scouts have no specific policy concerning AIDS. If the local "pack" or "den" decided they didn't want Alex there, he could be thrown out. Needless to say, I was not happy with this.

I approached the local den leader and scout master. Both have been very supportive. The current plan is to meet with parents and tell them (along with some training) that a child in the pack has AIDS (unfortunately Alex is no longer asymptomatic). If any parents want to make a fuss, they will be assisted in finding another pack for their children to join... but Alex will NOT be thrown out. This Cub Scout Pack, by the way, is sponsored by a Baptist Church.

3. One instance of support and understanding that sticks out in my mind is a conversation I had with Alex's teacher at the beginning of this school year. She shared with me about her meeting with the principal and vice principal. They told her a child who has AIDS would be attending school and asked if she would object to him being in her class.

She told me: "I was stunned at first... I didn't know what to say. Then I asked myself 'What would Jesus do?' and the answer came easy. Of course, I'll take this child in my class and into my heart." If more people would take

the time to ask themselves that question when faced with a tough decision, the world would be a much better place and life would be so much simpler.

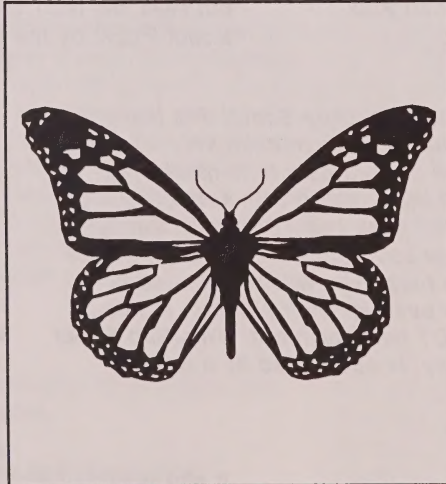
Conclusion

Though we have experienced hatred and bigotry, we have also received a great deal of support and friendship from many people. I remember as a child learning about Jesus ministering to the sick and lame... even to the lepers who were outcasts of society.

People with AIDS are humans too. Like everyone else they have a need to be

needed... to fit in. People ask me, "What can I do to help?" I tell them that the most important thing they can do is to be a friend. That may mean just going through life as usual, providing a shoulder to cry on, maybe a comforting hug, or maybe just simply being there. Treating those with HIV/AIDS with kindness and dignity is by far the greatest gift that can be given. The "Golden Rule" applies, "Do unto others as you would have them do unto you."

Richard B. Cory lives in Chesapeake, VA. He is an American Red Cross certified HIV/AIDS instructor and a member of the National Association of People with AIDS (NAPWA).



Pastoral Care: A Parent's Perspective

by William Nunn

The topic of pastoral care gives me great pain. I am very sad that so many clergy will not visit a person with AIDS. I am also sad that some who do visit spend their time reprimanding the person for the "evil life" they have lived.

This article was written as a result of my efforts to find a pastor to go to our son after he entered the hospital. Of all I contacted, only two offered to go. One did not get there in time and the other walked into the room, stared at him, and left without a word. I was devastated at this lack of pastoral care. I was not aware, at the time, of the clergy person who had counseled him in his earlier hospitalization. My son had told me that he had made his peace with God, but I had no idea how he had done so. He told me that no one had come.

Those of us who try to live by the Bible know it tells us about how we should live, though the Bible is interpreted in different ways by different denominations and even by different people within denominations. These beliefs can be argued without end. Some religious teachings say that our behaviors can cause our downfall and sentence to hell. However, we also have been taught that the worst of sinners can be forgiven and receive the life everlasting. We know that, in Christianity at least, even a last breath reconciliation with God can be made.

How can clergy, if they profess to be doing the work of the Lord, refuse to minister to

people who are HIV positive? We read in the Bible that Jesus worked with lepers and prostitutes, healing and bringing them to salvation. Would he not be working with people with AIDS and others who suffer in so many ways if he were here today?

A pastor need not fear contamination from AIDS when visiting a person who has HIV. Talking, holding the hand, praying, and counseling are all safe. No one gets AIDS

that way.

Those who stand at the door of the room and yell a prayer at the sick person may as well stay home.

This is of no help. Rejection

is obvious, or is it fear... or both?

A pastoral visitor may suffer emotional strain if a person tells them a life story of drug use or multiple partner sex. Pastors must keep in mind that the story may be poured out in an effort to shock, to see if the pastor will flee the room. Once the person's story is out in the open and the visitor accepts it, then the tension goes away and is replaced by trust. Then progress can be made and real healing can happen.

The important thing for pastors is to give people with HIV counsel, comfort, hope for the hereafter. Ranting at them about sin is not going to help or solve anything. If you are a pastor who thinks it is helpful to tell persons with AIDS that they are going to hell for their sins, please stay home. If you feel you can tell them about the grace and forgiveness of God, then go and help them find their peace.

I hope that clergy will learn to comfort and counsel persons living with AIDS. Pastoral care for persons with HIV is not much different from care for any person who has a terminal illness. All who are ill need and appreciate similar things: sincerity, concern, care, comfort, intercessory prayer, and love. They need to know about and experience God's love.

I mentioned earlier that initially I did not know about the pastor who visited my son when he was first hospitalized. She had not been without shock in the whole matter of his life story. His story was not a pleasant one, but she reacted calmly and with unconditional love. He responded when he knew she was sincere. She spent much time with him and helped him work through his life and his feelings. She helped him make his peace with God. Later she assured us that he had made

the right decisions and that he was going to live in the house of the Lord forever.

I am thankful for those blessed pastors who go to a person who has HIV with unconditional love and work with him or her to dispose of the guilt and pain. These pastors bring the person to the grace of God and help them feel hope, no matter how late the hour. I am eternally grateful to this lady for her willingness to minister to my son, someone she had not known previously and someone who desperately needed her counsel and guidance.

William (Bill) Nunn is recently retired from managing a retirement facility in Pennsylvania. His son died of HIV related disease. He consented to share some of his experiences with us, and thus with you, concerning watching ones child live and die with AIDS.

Try CAM -- the Computerized AIDS Ministries Network -- Now!

CAM, the Computerized AIDS Ministries Resource Network is now available for you to try. It is designed to provide a medium through which people may obtain current information and resources to assist in ministering to persons impacted by HIV disease. CAM also provides services that will help those engaged in HIV/AIDS ministries to interact with one another, thus providing mutual support and interchange of ideas and methods.

The CAM Network is a project of the Health and Welfare Ministries Program Department of the General Board of Global Ministries of the United Methodist Church. **You can access CAM through your personal computer by dialing one of our two numbers 1-212-870-3953 or 1-800-542-5921.** *If you call the first number, you save Health and Welfare Ministries money and help it maintain the 800 number for those who cannot afford the long distance calls.* Donations help pay for CAM's costs and to help continue making a free BBS available for those who could not otherwise afford to be on it as much as they need to be for HIV information and support.

In order to try out CAM you will need the following items:

- A personal computer.
- A modem for the computer.
- A telephone line into which the modem can be plugged.
- A communications (or terminal emulation) program for the computer.

If you already have these items, and know something about using them, you can dial into CAM now. If you decide to directly contact CAM, your communications parameters should be set to no parity, 8 bit word length, 1 stop bit. Any common speed up to 9600 bits per second (bps) may be used. When CAM answers the phone you will find that the system is all menu driven. For first time users you are asked to identify yourself with several questions.

If you also need a communications program, one that works well with CAM and runs on an IBM/compatible PC can be downloaded or we can send you a diskette. If you are just getting started with computers, you can call 212-870-3909 and request a *CAM User Packet*, that will include the manual and a diskette with the communications program, CILINK.

The CAM Network has as its heart a bulletin board system (BBS). A successful bulletin board service requires active rather than passive participation. CAM has information files in its library, which grow weekly. Many of these information resources have been shared with CAM by others involved in AIDS ministries. With CAM you can send a copy of materials you have produced (providing you have it on a computer file) by uploading your file(s) from your machine to CAM. This is the reverse of what you might usually do (download files from CAM to your machine), but this will allow the CAM information resources to grow more rapidly than if our office staff is solely responsible for providing information. Try CAM today!

HIV / AIDS MINISTRIES NETWORK FOCUS PAPER # 23

A NETWORK OF UNITED METHODISTS AND OTHERS WHO
CARE ABOUT THE GLOBAL HIV/AIDS PANDEMIC AND
THOSE WHOSE LIVES HAVE BEEN TOUCHED

ABOUT THIS ISSUE

March 1994

Dear Network Members:

This edition of the *HIV/AIDS Ministries Network Focus Paper* looks at issues of starting and maintaining support groups, with specific information related to the uniqueness of working with persons living with HIV. It continues the emphasis begun in *Focus Paper #22* which focused on the issues of pastoral care with persons living with HIV/AIDS. The response to that edition has been among the best we have seen within our focus paper series.

The department receives calls every month seeking information about starting and facilitating support groups for persons living with HIV and their loved ones. This focus paper draws on the considerable bank of information available regarding establishing and running support groups. It is the first in a two-part series with *Focus Paper #24* (to be produced in June) providing further helpful information and resources regarding support group

IN FOCUS PAPER # 23

About This Issue **cover**

"SUPPORT GROUPS:
PLACES OF HEALING"
by Nancy A. Carter **3**

"COMPUTERIZED
AIDS MINISTRIES (CAM):
A FAMILY SUPPORT
GROUP"
by Nancy A. Carter **11**

"THERE FOR THEM:
A GRASSROOTS SUPPORT
NETWORK" **14**

HIV/AIDS Ministries Network Focus Papers are a publication of the Health and Welfare Ministries Program Department, General Board of Global Ministries, The United Methodist Church, Room 350, 475 Riverside Drive, New York, NY 10115. Phone: 212-870-3909. FAX: 212-870-3873. Focus Papers, unless otherwise noted, may be quoted, reproduced and distributed with credit being given to Health and Welfare Ministries Program Department and the authors.

development and an annotated bibliography of additional resources which can be secured to assist you in setting up supportive and safe support groups for persons living with HIV and their loved ones.

Emotional/spiritual support for persons infected with HIV and their loved ones and care partners is a vital aspect of living with HIV. The needs for support groups in every community and almost every church are significant. Sometimes getting started seems a daunting task. **Focus Paper #23 and 24** aim at providing you the resources and basics for developing an appropriate response within your congregation and community.

The information in the Family Network section comes from information gathered by inviting users of the Computerized AIDS Ministries (CAM) Resource Network to tell us their experiences within support groups. In these letters you will hear the voices of family members who have had or who are dealing with loving someone infected with or affected by HIV. Read them carefully and thoughtfully. If your church or community does not provide support groups for persons struggling with HIV, these reflections may serve to motivate you to see that such support is offered.

CAM continues to be a major resource for those affected by HIV/AIDS, with more than 400 users. CAM is active over 20 hours per day. Within the first 7 months of operation, it has logged more than 25,000 calls and 48,000 messages. A recent newspaper article referred to CAM as a "drive-in church along the new communication's super highway." If you haven't done so, we invite you to try it.

"There For Them" is an announcement of a pilot project between the Iowa, Kansas East and West conferences to establish a support network for persons living with HIV and their loved-ones. It is an interesting project which the department will be following.

With kindest regards,

Cathie Lyons
Associate General Secretary

Charles R. Carnahan
Executive for HIV/AIDS Ministries

Support Groups: Places of Healing

by Nancy A. Carter

The Rev. Dr. Nancy A. Carter is a consultant for the Health and Welfare Ministries Program Department, GBGM, UMC. She is an editor/writer and the sysop (system operator) for CAM, the department's computerized AIDS Ministries electronic information service. She has written many articles, including a number on HIV and the church, and three books, including Jesus in the Gospel of Matthew: "Who Do You Say That I Am?" published by the Women's Division, GBGM, UMC, in 1993.

*The silence of churches, synagogues, and mosques across the nation--the refusal to listen with love--serves to push aside people with HIV/AIDS. The church, and that means all people, must stop pushing away our brothers and sisters with AIDS; we must stop trying to put them out of our lives and out of our families. The church is supposed to bring people together, not to leave them out in the cold. The church is to be a place of healing. -- **The Rev. Cecil Williams, Glide Memorial United Methodist Church, San Francisco, CA** [1]*

Support Groups Are Important

Support groups help meet the needs of persons living with HIV/AIDS, their loved ones and caregivers. Caregivers include a variety of people--loved ones of persons living with AIDS (PLWAs), buddies, health care professionals, and facilitators of support groups. Support groups can:

- provide people with HIV a relaxed and informal place to share their experiences and build new friendships;
- help caregivers to renew their faith

and confidence in the face of devastating losses;

- give couples (at least one of whom is HIV positive) an opportunity to discuss relational, legal, health, and other issues that concern them;
- provide specific groups of people--such as women, persons over 50, teenagers, African-Americans, Spanish-speaking people--a support group of their peers to discuss their experience of HIV in their lives.

Support groups are especially important to persons who are HIV positive. So many emotions confront people after they have been diagnosed. As they face changing social supports and financial situations, they can become frightened, bewildered, and worried. When others reject them and treat them inappropriately, they can become depressed, angry, and isolated.

In support groups, PLWAs meet others who have had similar experiences. They learn they are not alone and that they can build a new life. A participant in a support group wrote on the CAM electronic bulletin board about a group he had belonged to:

I could share with these people my deepest secrets and still be loved. I would give up an arm or leg to have a new support group. I have tried to start one but it never panned out.... When I first became sick it was the group that gave me the strength to keep going. In the group we talked about life and we also got a guest to come in and teach us nutrition, legal aspects, alternative medicine

and many other programs.... It saved my life so I know how important it can be for others.

HIV support groups often become a major source of love and acceptance. Usually people gain acceptance, support, nurture, and intimacy from their birth families, close friendship groups, and/or religious groups, such as churches and synagogues. However, too often, these groups reject individuals when their HIV positive status becomes known, especially if the person contracted AIDS from IV drug use or same gender sex.

Loved ones of PLWAs can also benefit from special support groups to deal with their issues, including their feelings about caregiving, fear of contagion and infection, grief, changed social conditions, health concerns, and obsessional thoughts.

Informal caregivers... may face the same issues of anticipatory loss and grief, isolation, helplessness, and hopelessness as HIV patients.... Support groups can help caregivers meet the challenges of social isolation and lack of a support system and reduce stress, enhance coping skills, and avoid burnout. Groups enable caregivers to discuss concerns with others sharing the same experiences and emotions and to work out complex feelings of worthlessness, frustration, or alienation....[2]

HIV negative persons are another group that need support groups. Those who have lost friends, neighbors, and loved ones to AIDS can suffer from "survivor syndrome."

Symptoms of this state are intrusive images of disaster, psychic numbing, struggles to find meaning, and guilt.[3] Persons feeling this way are liable to participate in self-destructive behaviors, such as overt and covert suicide attempts. They may start to have unsafe sex. A goal of survivors' groups is therefore to keep their members HIV negative: "'We are survivors--so far--but there is the threat of becoming infected and the responsibility of remaining virus free,' said Will Johnston [a participant in a HIV negative support group]...."[4]

Types of Support Groups

Four general types of support groups exist. Support groups are small groups that gather for support for dealing with a shared concern or experience and

Support groups are especially important to persons who are HIV positive. So many emotions confront people after they have been diagnosed.

1. follow a suggested, often ritualistic, format; have established written guidelines; but use rotating facilitators.

Common examples: 12-step groups, including HIV Positive 12-step groups; some types of church groups meeting for prayer, action, and/or study.

2. use rotating facilitators or no designated facilitators. They follow either a loose regular format or are "free form."

Common examples: consciousness raising groups; some types of church groups meeting for prayer, action, and/or study, such as covenant groups; social groups.

3. are facilitated by trained volunteers.

These groups usually have some kind of verbal or written agreement about the format of the meetings and the ground rules for the group.

Common examples: a variety of HIV-related support groups sponsored by AIDS support and other organizations; bereavement groups; church small groups; parents' groups, social action groups.

4. are facilitated by trained professionals. The format and guidelines of these groups vary with the professional's style of leadership and the purpose of the group.

Common examples: HIV/AIDs support groups run by therapists, social workers, clergy; group psychotherapy, general groups and groups focusing on a certain issue such as physical abuse or recovery from addiction; support groups for trained volunteers facilitating support groups.

When established with the appropriate guidelines, support groups provide a nonjudgmental environment where people with similar experiences vent their feelings; work on their day-to-day problems; explore issues that concern them, including spiritual issues; and widen their base of friends.

This paper focuses mostly on how congregations can sponsor the third type of support group, those facilitated by trained

volunteers, with some emphasis on groups led by clergy. The example of a support group that is used is for HIV-positive people.

The groups described in this paper are not therapy-oriented groups. Sometimes PLWAs need to be in therapy support groups; most often other types of groups are more appropriate. Additionally, we must take care not to convey the message that just because a person is HIV positive she or he needs psychotherapy. This approach can be especially problematic when dealing with persons from cultures that are not psychotherapy-oriented and get their support and guidance from their own peer groups and/or religious leaders, not to mention those who cannot afford psychotherapy.

Getting Started

There are as many ways churches can start and maintain HIV-related support groups as there are groups. First of all, your church should assess if there is a need for such a group and the type of need that exists. At this step, pay attention to who has suggested a support group--the group to be served and/or the group offering the service.

Be sure those to whom the service is offered also feel the need for a support group.

Sometimes churches that want to start an HIV support group have their own "agenda," such as gaining new church members,

bringing the gospel of Jesus Christ to the participants in a doctrinaire way, or helping group members to leave their "sinful lifestyle." In their book, *AIDS and the Church: The Second Decade*, Earl E. Shelp

HIV negative persons are another group that need support groups. Those who have lost friends, neighbors, and loved ones to AIDS can suffer from "survivor syndrome."

and Ronald H. Sunderland emphasize:

AIDS ministries are primarily ministries of support, nurture and consolation. They are not primarily evangelistic ministries in the sense of pressure to convert to a particular faith or morality. To view evangelism as the primary or sole objective of ministry to people with AIDS is to misunderstand ministry and probably will be counterproductive with the targeted audience.

... "Saving" people, it should be remembered, is God's business. Thus, the purpose of all ministry, including AIDS ministry, is to represent God's love for all humanity, without condition, and to embody and express that love in all human relationships.[5]

Another step is to find out if that the service is offered elsewhere. If support groups exist and no more are needed at the time, ask those groups if they have needs such as referrals, low cost space, pastoral counseling, safe religious space for PLWAs.

If you determine that people need one or more support groups, secure appropriate persons to be facilitators. If these volunteers are inexperienced with leading HIV support groups, hold a training event or send them to a training event. A local HIV support organization; a social worker, pastoral counselor, or psychotherapist experienced with working with people with HIV; and/or instructional training booklet can assist your training. **Focus Paper #24** will contain an annotated bibliography of resources that can help you in training and carrying out support groups.

Always involve potential group members in the planning for the training of the

facilitators and for the purpose of the group. "Ownership" of the group by its members is a vital issue. Group members should share in the leadership at every stage of planning.

Groups can be open-ended or time-limited. They should have a specific focus, such as a group for HIV positive people, a

There are as many ways churches can start and maintain HIV-related support groups as there are groups.

group for caregivers, or a group for women who are HIV positive and/or at risk for becoming HIV positive. Discussions can center on a variety of topics, including medical information, treatment options, common experiences, or physical, emotional, and/or spiritual support.

Set an agenda, a regular meeting time, and a convenient location. Advertise, as appropriate. Make phone and personal contacts to let people know of the group.

The Role of the Facilitators

A support group, whether formed from a spiritual, pastoral or psycho/social perspective, must be facilitated by experienced, compassionate and competent persons. Good facilitators are, in the words of pastoral counselor Howard Clinebell, "group-centered leaders," and "midwives." He has written that "Their job is to help the group achieve an emotional climate and a level of communication, which will facilitate the growth of all group members." [6] Facilitators model an attitude of support,

caring, concern, and respect for all.

Creating an atmosphere of respect and dignity and maintaining it is of utmost importance, especially for groups of HIV positive people. In other contexts, PLWAs often experience rejection and oppression because of their positive status, history of IV drug use, and/or their sexual orientation/identity, race, class, nationality, or gender. Individuals need a safe place where they can be themselves.

Facilitators set basic boundaries, making it clear that the group norm is tolerance of each individual's uniqueness. They demonstrate respectful and caring behavior by listening carefully to what each group member says and addressing each one with respect and dignity. They model asking questions and expressing disagreements in a supportive, non-threatening way.

The facilitators and group should develop group guidelines. For instance, an important ground rule is that no physical violence or threats of physical violence will be tolerated. The group may want to be a non-smoking group.

Make a group agreement that members who are not already in a sexual relationship with another group member must not enter into one during the time period the group meets. Speaking of support groups whose purpose is healing and/or recovery, feminist

psychotherapist Charlotte Kasl says that, in a healthy support group:

Sexual or emotional exploitation is not accepted as part of the norm. People do not emotionally, sexually, or in any other way exploit each other. The group is not used as a place to find sexual or dating partners. (Remember groups often become one's psychological family and it is incestuous to have sex with one's brothers and sisters.) If two members become involved, one should leave. [7]

This boundary is not intended to be sex-negative, but some may hear it as so. Spend time discussing it as is needed.

This boundary is intended to maximize healing and prevent abuse that happens in both heterosexual and gay/lesbian group relationships. Kasl has written extensively of the sexual abuse of women by men in Alcoholics Anonymous. Sexual exploitation is not limited to heterosexual men, or men in general. Abuse can be initiated by either gender and by persons of all sexual identities/orientation.

Boundaries will vary from group to group, according to its context and needs. Another very important concern is confidentiality. Be sure the group understands that "what is said in the room stays in the room."

Co-facilitators can be a better leadership model than a single facilitator. For example, where the group is a mixed-sex group, a male and female team can be very effective.

Good facilitators are, in the words of pastoral counselor Howard Clinebell, "group-centered leaders," and "midwives." He has written that "Their job is to help the group achieve an emotional climate and a level of communication, which will facilitate the growth of all group members."

If at least one of the facilitators is HIV+, the group may experience this as especially affirming and encouraging. An important key, of course, is that the co-facilitators get along and work well together.

The Life of the Support Group

Though each group is unique, support groups tend to move through certain stages. The facilitator should know these stages and phases and be ready to guide the group.

Early Stages in a Group[8]

People newly-diagnosed with HIV often say, "I don't need a support group." Sometimes this reaction covers some type of fear about joining a group. Perhaps the person has never been in a support group setting before or has had a negative experience with a small group. The person may also realize deep down that attending a group will "bring home" the reality of his or her diagnosis. Change itself--just meeting new people-- can be scary.

Most people experience coming into a support group as a threatening situation. Especially in their first few meetings of a support group, some may show a great deal of superficiality and politeness. Others may reveal fears and anxieties, such as hesitancy, aloofness, or silence.

About the second or third group meeting, confrontations and oppositions begin. For example, if a number have told stories of being rejected by others because of their HIV positive diagnosis, those who have not experienced rejection may share their experience. The facilitator must make it clear

that expression of differences, disagreements, and a broad range of feelings, including anger, are all right.

Confronting differences can be especially difficult for persons with AIDS dementia, who may think a question or challenge is an assault, an attempt to do harm. For this reason, confrontation of people with AIDS dementia must be done carefully in an

Another very important concern is confidentiality. Be sure the group understands that "what is said in the room stays in the room."

atmosphere of unconditional acceptance. The facilitator and group must make a special effort to create a warm, caring, safe environment for them.

Later Stages of a Group

If the group is truly supportive, trust evolves and deep friendships are formed. Then the "hard work" begins. Individuals freely express their anger and resentment, their fears and anxieties concerning illness and death, and also their affirmations and celebrations of life.

A support group for HIV positive persons probably will be ongoing, rather than time-limited. New group members will come (a clear process for new group members entering should be established). More "senior" group members may leave as a result of increased illness or death.

The congregation and pastor(s) can help

support these groups, informing them about the availability of services, such as individual pastoral care, congregations that welcome persons with HIV and their loved ones, weekly prayer lists, and sanctuary/chapel space for healing services, memorial services, and funerals.

Deal with group transitions openly--both "arrivals" and "departures." Welcome new members and invite everyone to introduce themselves.

Discuss sicknesses and deaths of members. If the group is engaging in a "conspiracy of silence" about the sickness or death of a group member, a facilitator might say, "I miss R... so much." or a similar comment to signal that it is OK to talk about sickness, death, and grief.

If group members seem ready, facilitators should encourage them to visit any member who has been hospitalized or is homebound. That members visit each other will reassure those still attending the group that they will not be forgotten when they if are unable to come. In the group, be sure to invite visitors to process their feelings about their experiences.

The tone and content of meetings will vary. In some meetings, members will focus on issues of death and dying. At others, the atmosphere will be light. Facilitators have to be intuitive and sensitive to the group's needs. Avoid pressing too hard while at the same time knowing when to give the group

a little push.

Although HIV support groups must experience a lot of mourning, celebrations should also be a part of group life. Plan special events and get-togethers, particularly during the holidays. When a member returns after an illness, have a special meal to welcome him or her back.

All of us are *living* with AIDS. Some of us are HIV positive. *Life* calls for celebrations.

Though each group is unique, support groups tend to move through certain stages. The facilitator should know these stages and phases and be ready to guide the group.

Conclusion

HIV/AIDS is difficult for all of us, whether we admit it or not. It is affecting us as individuals, a community, a nation, and a world at every aspect of our existence. HIV has forced many of us look at ourselves and the way that we, as a society, have treated not only PLWAS but all those with other illnesses, people who are elderly, and people who are physically challenged. One good result of this devastating crisis is that persons working with HIV have joined together in a common cause with people from a variety of backgrounds, races, religions, economic classes, and different sexual/gender identities.

We need to find new ways to be supportive of one another, not only when confronting HIV, but in all dimensions of our common life. As we learn to be more supportive, loving, and caring of each other, we will grow in ways God has called us to grow.

ENDNOTES

[1] Cecil Williams, *No Hiding Place: Empowerment and Recovery in Our Troubled Communities* (San Francisco: HarperSanFrancisco, 1992), p. 216.

[2] Ken Pinhero and Cathy Cassel, "Group Support for Caregivers" *Focus: A Guide to AIDS Research and Counseling* (01/91) Vol. 6, No. 2, p. 1. As reported in The Centers for Disease Control and Prevention (CDC) National AIDS Clearinghouse Daily Summary. Copyright 1991, Information, Inc., Bethesda, MD.

[3] Rachel Schochet, "Psychosocial Issues for Seronegative Gay Men in San Francisco," *Focus: A Guide to AIDS Research and Counseling* (08/89) Vol. 4, No. 9, p. 3. As reported in The Centers for Disease Control and Prevention (CDC) National AIDS Clearinghouse Daily Summary. Copyright 1989, Information, Inc., Bethesda, MD.

[4] Renee Graham, "The Negative Experience," *Boston Globe* (01/21/92), p. 51. As reported in The Centers for Disease Control and Prevention (CDC) National AIDS Clearinghouse Daily Summary. Copyright 1992, Information, Inc., Bethesda, MD.

[5] Earl E. Shelp and Ronald H. Sunderland, *AIDS and the Church: The Second Decade*, revised edition (Louisville, KY: Westminster/John Knox Press, 1992), pp. 136-137.

[6] Howard Clinebell, *Basic Types of Pastoral Care and Counseling: Resources for the Ministry of Healing and Growth*, revised and enlarged (1966; Nashville: Abingdon Press, 1984), p. 356.

[7] Charlotte Davis, *Many Roads, One Journey: A New Understanding of Recovery*, (New York: Harper Collins, 1992) p. 293.

[8] Parts of "Early Stages," "Later Stages," and "Conclusion" have been adapted from "HIV/AIDS Counseling for Today and Tomorrow," chapter six on support groups, an unpublished manuscript by Mark A. Bonacci and *AIDS Interfaith Network, Inc of North Texas Care Team Training Manual* by Charles R. Carnahan and Robert E. Hensley, 2nd edition (Dallas: AIDS Interfaith Network, Inc., 1990). Copyright 1990. Used with permission.

U.M. FAMILY HIV/AIDS NETWORK

A NETWORK OF UNITED METHODIST FAMILIES AND
OTHERS WHO HAVE BEEN TOUCHED BY HIV/AIDS

Computerized AIDS Ministries (CAM): A Family Support Group by Nancy A. Carter

CAM is a bulletin board service (BBS), a form of electronic communication sponsored by the Health and Welfare Ministries Program Department of The United Methodist Church. CAM's purpose is to give HIV/AIDS information and support. People who have computers and modems can call CAM and communicate with others in forums, public areas where they can read and write messages to others. They also have access to hundreds of files about HIV.

As I was preparing this focus paper, I sent a message to CAM-users asking them to share their experiences with support groups. I was thinking of small face-to-face groups. The first group they thought of was CAM! Following are three responses:

...All I can tell you from the experience I have been through with [support groups] is that without them, I may not be around here to be with all these other fine folks here on CAM. They are a God's-send... You are able to really get down with your feelings and let everything loose with your self and not have to worry about how others may feel or think about what you are going through.

You are running your own support group right here on the CAM board.... A lot of people call this board for the feeling that they can let go of all their feelings that may be troubling and not have to worry about feeling in a strange place. I commend you for all you have done and look forward to many more times here on this board. Thank you, Nancy for being here and the U.M.C for allowing this board. God bless you.

FB

I really can't over-emphasize how much support groups have positively effected my life!

I found out I was HIV+ when raising my life insurance to better cover my wife and 4 kids. The doctor told me I could expect to live about 2 years. Of course, I was devastated and knew no one to turn to.

The support I found came from the support groups offered through the electronic media and my home computer. I quickly found close friends who showed me that my life is not over and we are not alone! I have also learned enough from my support system that I can manage my health care with my doctor instead of being led around by doctors who for the most part know only small amounts about HIV infection.

These support groups have truly added to the length and quality of my life. I learned the recommended treatment for thrush (which I had fought for many months) through this media and then directed my doctor to the proper medication which quickly healed me.

My valuable experiences, as well as the friendships and the knowledge gained through electronic support is far too important to set a price on. The sharing of practical HIV treatment and information has also helped to advance the way we live with HIV for ever increasing amounts of time. The gratitude I feel for the people who make this possible is immeasurable!

Those of us who post on forums like CAM and others--we lay our hearts out for all to see! Most of the time these forums offer the love, honesty, and compassion that those of us who "reside" on them truly need. There are, occasionally, people who invade these havens with agendas of hate or intolerance or just to amuse their warped selves. These people do a lot of emotional damage and we are fortunate to have a well-regulated bulletin board that doesn't really censor, but never tolerates hate and prejudice to the people who need this support so badly.

ME

As a mother of a son who tested positive to the HIV virus back in 1984, I would have loved to have been part of the support of this group or any other group that could have offered me the love and support that this board does. I didn't have it.

John's illness came to a head in January when he was diagnosed with AIDS-related lymphoma. His neurologist just happened to be the neurologist I've been seeing for the last 26 years for my epilepsy....

Our neurologist told me last February to get into group therapy, see a psychologist or counselor, or somehow find a support group because the water was really going to be rough

for me. He told me that the treatment they were giving John was only effective in biding time, but to his knowledge had never been successful in a cure. They'd tried other methods first but they were at a point where they were running out of options.

My [electronic support] group [was] wonderful during John's illness. They were always available. One member even checked onto the Internet every two hours-- even when he was at work. (It helps when the guys are bosses.)

... Dave ... told me about CAM.... I called to be welcomed by G. C. and C. L. and a whole group of warm loving people.

I know that if John had had that kind of support in his last illness, it might have been easier for him. He did participate on several bulletin boards but not in an atmosphere where he was accepted for himself. The BBSs he participated on were openly hostile to the homosexual community. He spoke out for anything he considered wrong and right...

I honestly believe that I am stronger and wiser for having been a participant on CAM and my other [BBS] support group.... We've grown to love one another and are able to help each other during the worst times in our lives. I can only thank God that I was blessed to find CAM and the support I did.

... I took care of John in hospice and was with him when he passed away.

CG

If you have a computer, modem, and communications program, you can all CAM at 212-870-3953. Set your communications program to 8,N,1. CAM accepts any common modem speed up to 14.4 bps.

There For Them: A Grassroots Support Network

I recently received a call from Rev. Steve Wainwright in Macedonia, Iowa. We talked about developing a response to address the needs of individuals and families struggling with the issues of a loved-one who was infected with HIV. His interest was to develop a response which would deal with the realities of families concerns for unanimity, confidentiality and still provide support. What follows is a summary of his program (taken from a letter distributed in the Iowa Conference) which is a pilot program currently being developed between the Iowa Annual Conference and the Kansas East and West Conferences. It's an idea your church or conference may be able to adapt to your situation.

Rev. Charles R. Carnahan

A grass-roots vision to establish an AIDS support network has recently been proposed by Rev. Steven Wainwright in Macedonia, Iowa. Rev. Steven has found great reluctance by families who are personally affected by AIDS to share their burden. What's happening is that they find themselves isolated, overburdened, filled with guilt, shame and little support, not unlike the lepers of old who lived in caves away from everyone.

Rev. Steven proposes a ministry called "There For Them", where churches would spiritually adopt a son or daughter who has AIDS and their family ... sending them cards and letters, praying for them, and ministering in whatever other way might be most healing.

Since many families have fears in sharing their burden, Rev. Steven suggests that we first adopt those from other conferences, where their anonymity would better be protected. He has contacted Bishop Fritz Mutti of the Kansas Conference. Bishop Mutti is willing to partner with us (the Iowa Conference) in this ministry.

Of course, we must reach out to those in our own communities and shall. Hopefully this first journey to Kansas will lead us home .. so we might be "There For Them" in every home and church in Iowa.

AIDS MINISTRIES NETWORK -- FOCUS PAPER

ORDER FORM

(AIDS Ministries Network Focus Papers are published by the Health and Welfare Ministries Program Department, General Board of Global Ministries, The United Methodist Church, Room 350, 475 Riverside Drive, NY, NY 10115. Direct inquiries and request to Reverend Charles Camahan, Executive for HIV/AIDS Ministries at the above address or by phone 212-870-3909, fax 212-870-3873.)

If you would like to receive previous Focus Papers, please indicate your choice with a check mark. Return this form to the address above.

FOCUS PAPER TITLES

- | | |
|--|---|
| ☐ #2: God's Love We Deliver: Home Delivered Food Service | ☐ #14: The Epidemic of HIV Infection in the United States |
| ☐ #3: AIDS Ministries and The United Methodist Church | ☐ #15: The Global AIDS Pandemic: Facts and Figures |
| ☐ #4: Living with AIDS: A Personal Journey | ☐ #16: Binding Up the Brokenhearted Children |
| ☐ #5: AIDS Bibliography: Selected Resources for Church Educators | ☐ #17: Women Don't Get AIDS: They Just Die From It (Part I) |
| ☐ #6: AIDS: A Covenant to Care | ☐ #18: Women Don't Get AIDS: They Just Die From It (Part II) |
| ☐ #7: Spiritual Life Retreats Enrich AID Ministries | ☐ #19: The Healing Ministry of the Church in the Second Decade of AIDS |
| ☐ #8: This Is The Day (A Care Provider's Story) | ☐ #20: Have I Died Already or Am I Still Alive |
| ☐ #9: AIDS Information and Resources To Meet Your Needs | ☐ #21: IXth International HIV/AIDS Conference: Highlights |
| ☐ #10: Threads of Love: A Tapestry of Remembrance (The NAMES Project AIDS Memorial Quilt) | ☐ #22: Pastoral Care and HIV/AIDS Ministry |
| ☐ #11: Children and HIV Infection | |
| ☐ #12: Basic Information on AIDS/HIV Infection and Related Illnesses | |
| ☐ #13: AIDS and the Power of God's Goodness and Grace | |

Name: _____

Address: _____

City/State: _____ Zip: _____

**RELATED RESOURCES AVAILABLE FROM
HEALTH AND WELFARE MINISTRIES PROGRAM DEPARTMENT
GENERAL BOARD OF GLOBAL MINISTRIES
UNITED METHODIST CHURCH**

— **"A Statement On Acquired Immune Deficiency Syndrome The Council of Bishops -- The United Methodist Church,"** April 1988.

— **"Report And Recommendation Of The Interagency Task Force On AIDS To The 1992 General Conference,"** Interagency Task Force on AIDS, Health and Welfare Ministries Program Department, May 1992.

— **"AIDS And The Healing Ministries of the Church,"** a resolution by the 1988 General Conference of The United Methodist Church, May 1988.

— **"Suggested Principles and Guidelines Regarding Work Place Policies on HIV Infection And Related Illnesses,"** Health and Welfare Ministries Program Department, revised 1994.

— **"Resources For AIDS Education,"** a resolution by the 1988 General Conference of The United Methodist Church, May 1988.

— **"Things Conferences can do in AIDS Ministry/Education/Advocacy/Direct Service,"** Health and Welfare Ministries Program Department, revised 1993.

— **"The Church and the Global HIV/AIDS Epidemic,"** a resolution by the 1992 General Conference of The United Methodist Church, May 1992.

— **"Things for Institutional and Direct Service Ministries to Keep in Mind in Response to the HIV/AIDS Epidemic,"** Health and Welfare Ministries Program Department, revised 1993.

— **"Care-Giving Teams for Persons with AIDS,"** a resolution by the 1992 General Conference of The United Methodist Church, May 1992.

— **"Activities for Individuals and Churches Developing HIV/AIDS Ministries,"** Health and Welfare Ministries Program Department, revised 1993.

NAME: _____

ADDRESS: _____

CITY/STATE: _____ **ZIP:** _____



SCHOOL OF
MEDICINE

The University of Alabama at Birmingham
Department of Medicine
Outpatient Clinic
908 20th Street South
Birmingham, Alabama 35294-2050

Mary X Deaton

Deby Wright
Covenant Metropolitan Community Church
1001 Fourth Avenue South
Birmingham, AL 35205





Department of Medicine

Wednesday, June 15, 1994

Deby Wright
Covenant Metropolitan Community Church
3001 Fourth Avenue South
Birmingham, AL 35205

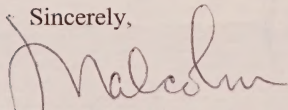
Dear Deby:

I want to invite you personally to attend *Friday Morning Grace*, an opportunity for individuals to learn about HIV and AIDS, and how congregations can make a difference. It is repeated every Friday morning of the year, from 9:00-11:00 a.m. The group is limited to 12 persons each week to allow for dialogue and learning together. I've enclosed a brochure that describes the program in greater detail.

We will do three things after touring the UAB 1917 Clinic (the AIDS Outpatient Clinic): 1) Learn about the basics of HIV/AIDS from a member of our medical team or other AIDS educators in our community; 2) Hear a personal story from one of our patients and/or family members; and 3) Discuss a variety of congregational responses that can make a significant difference in the fight against the AIDS epidemic.

There is no cost but reservations are required. The program is repeated every Friday so that everyone who is interested can hopefully attend one week. It is a good first step for individuals and congregations who want to know where to start in AIDS ministry and education. Why not look at your calendar and call to reserve your place as soon as possible? You are welcome to invite other persons to come with you, just let us know how many. I look forward to seeing you soon.

Sincerely,



Rev. Malcolm Marler
Chaplain, 1917 Clinic

P.S. If you would like multiple copies of the brochure, just let me know.

*My prayers are with you all since
Cliff's death.*

The Clergy AIDS Education Project

The Clergy AIDS Education Project is an outreach effort by UAB and the Dixon Foundation to teach congregations how to make a difference in the AIDS epidemic through education and ministry development. The project is directed by Malcolm Marler. In addition to Friday Morning Grace, other programs include:

AIDS Care Team Training

AIDS Care Teams of 10-12 persons meet the practical and spiritual needs of a person with HIV/AIDS. A training program will be offered regularly for congregations as well as support and supervision for team leaders.

AIDS Ministry Resource Library

A comprehensive HIV/AIDS library of books, newsletters, journals, magazines, video, and audio resources to educate congregations about HIV and ministry opportunities. Resources are loaned at no charge.

AIDS Ministry Newsletter

A newsletter written for the faith community to encourage communication between churches/synagogues and all AIDS organizations regarding AIDS education/ministry.

AIDS: A Call to Compassion, Education, and Ministry

The first statewide AIDS Ministry Conference for congregations in Alabama on Thursday, October 20, 1994.

You or your congregation can help support The AIDS Clergy Education Project! Call Malcolm Marler for more information.

The UAB 1917 Clinic

The UAB 1917 Clinic was founded by its clinical director, Dr. Michael Saag in January, 1988. The five basic goals of the outpatient clinic are:

- Provision of care to HIV-infected patients;
- Coordination of social service support and family counseling;
- Conducting high quality research protocols in both the clinical science and basic science arenas;
- Provision of education to health care providers;
- Establishment of vital links with the patient community and general population through well-orchestrated outreach programs.

A team of physicians, nursing specialists, social workers, psychologists, pharmacists, lab technicians, and chaplains address the physical, emotional, and spiritual needs of patients, family members, and friends. Over 1,000 active HIV/AIDS patients are presently served.

On the research front, the Clinic is a hub for the 100 plus researchers at UAB who are working exclusively on HIV related problems. The 1917 Clinic is also one of 28 federally funded AIDS Clinical Trials Group sites.

For more information
or a reservation for Friday Morning Grace,
call Rev. Dr. Malcolm Marler, Chaplain,
AIDS Pastoral Education Specialist
at 205-934-1917.

An Opportunity for People of Faith
to Learn about HIV & AIDS, and
How Congregations Can
Make A Difference

Friday Morning

Grace

Giving & Receiving AIDS
Compassionate Education

Every Friday
9-11 a.m.
for Clergy and Interested Persons
in the Faith Community





What is Grace?

Friday Morning Grace is an educational opportunity for clergy and religious leaders in Alabama to learn about HIV infection and AIDS at one of the leading treatment and research clinics in the United States. The goal of the program is to encourage participants to respond compassionately to persons affected by HIV/AIDS through creative education and ministry.

The format of the program includes touring the UAB 1917 Clinic and:

Introducing participants to the latest information about HIV/AIDS from our medical team;

Personalizing the disease by hearing from one of our patients and/or family members;

Presenting a variety of congregational responses that can make a significant difference in the fight against the AIDS epidemic.

Pastors, priests, rabbis, congregational staff members, denominational leaders, and lay persons are welcome. There is no charge.

When does it meet?

The Program is repeated every Friday from 9:00-11:00 a.m. at the UAB 1917 Clinic, 908 South 20th Street (corner of 9th Ave. & so. 20th St.). Group size is limited. Parking is available in the rear of building.

Reservations are required by calling Rev. Dr. Malcolm Marler, Chaplain, 205-934-1917.

A prayer of thanksgiving. A power granted by God. A gift granted by one who need not do so.

Divine love bestowed freely upon humankind.

A disposition to be generous or helpful.

Respite, mercy, a reprieve.

What is AIDS?

Acquired Immune Deficiency Syndrome

AIDS is caused by a virus called HIV, which stands for human immunodeficiency virus. When someone becomes infected with HIV, the virus attacks the person's immune system (the system that defends the body from illness).

A person develops AIDS when his or her immune system becomes so damaged that it can no longer fight off diseases and infections. These diseases can include cancers such as a skin cancer called Kaposi's sarcoma, or a lung infection called pneumocystis carinii, among several others.

How is HIV Spread?

The three most common ways in which HIV is spread are:

- Having unprotected sex with someone who is HIV infected;
- Sharing needles or syringes with someone who is infected with HIV;
- From an infected mother to her baby during pregnancy or childbirth, or rarely through breast feeding.

How is HIV NOT spread?

- Unlike some viruses, HIV/AIDS is not spread through casual contact. Examples of ways that HIV is NOT spread are:
- Worshipping with a person who has HIV/AIDS;
- Sharing communion with a person who has HIV/AIDS;
- Sharing a meal with a person who has HIV/AIDS;
- Playing in the nursery with a child who has HIV/AIDS;
- Touching, shaking hands, hugging, or kissing a person with HIV/AIDS;
- Visiting the home or hospital room of a person with HIV/AIDS;
- Drying the tears of someone with HIV/AIDS.

"Approximately 1 out of every 250 persons in the United States is infected with HIV."

—Centers for Disease Control and Prevention, 5/5/94—

INTRODUCING . . .

AFFIRMING PERSONS - SAVING LIVES

AIDS Awareness and Prevention Education for Christian Education Settings

"The United Church of Christ has made a singular contribution to AIDS education. This is not only the first comprehensive AIDS prevention curriculum for churches, it's the best AIDS curriculum I've seen, period."

- The Rev. Laura Lee Kent-Smith,
Executive Director
AIDS Interfaith Network of New Jersey

Affirming Persons - Saving Lives integrates . . .

Christian Values, Bible Study & Theological Reflection

Complete, Factual Information About HIV and AIDS

Ethical Decision-Making & Decision-Keeping Skills

Risk Assessment Skills

Skills for Effectively Refusing Unwanted Invitations

Communication Skills

Mission Education for AIDS Ministry

In development for more than 3 years and field tested in UCC church schools and other settings, *Affirming Persons - Saving Lives* is teacher friendly and can be taught without special training.

Affirming Persons - Saving Lives is designed to address the real concerns of real people living in a world where HIV transmission is a tragic reality.

This curriculum has one primary purpose: to save human lives.

The *Affirming Persons - Saving Lives* curriculum package is sold only as a unit and includes:

- o **Introductory Resources**, including guidelines for implementing the curriculum in your church and articles addressing special AIDS education concerns.
- o Eight age-appropriate **Learning Series** -- detailed lesson plans for each of the following age groups in your church:

Adults	Grades 3-4
Parents	Grades 5-6
Preschool & Kindergarten	Youth
Grades 1-2	Intergenerational
- o Easy to photocopy **Handouts** for use with the Learning Series.
- o **Teacher Support Resources**, selected to increase your teachers' knowledge of, and comfort level with, the subject matter.
- o Two new, award-winning **Videotapes** for use with the Adults and Youth Learning Series:

Learning About AIDS -- a comprehensive presentation of basic HIV/AIDS information. (28 min.)

In the Day of Adversity -- poignant interviews with church members living with HIV/AIDS. (44 min.)

Pre-Paid Orders Only. For more information, write to:

**AIDS Ministry Program
United Church Board for Homeland Ministries
700 Prospect Avenue
Cleveland, OH 44115-1100**

Or telephone Patricia Houlehan at (216) 736-3271

*Strength and help
for a friend*

CareNotes
TAKE ONE - and take heart.
GIVE ONE - and give hope.

When Someone You Love Has AIDS

by Dan Grippo

Pat Greene, who lost her son Freddie to AIDS in early 1986, remembers how he was treated at the hospital. "They would leave his meals on a cart outside his door, in the hall. If one of us wasn't there to bring them in, he wouldn't eat."

When AIDS first came on the scene in the early and mid-1980's, people with AIDS and their loved ones faced rejection



on all sides. Thankfully, some of this is beginning to pass as people learn more about the disease. But, although the hysteria surrounding AIDS seems to be abating, this does not lessen the shock and grief experienced by those who learn that a loved one has AIDS.

Working your way through

If a close friend or relative of yours has AIDS, this is indeed a painful time for you. The observations in this *CareNote* may help to ease your pain and strengthen your spirit.

■ *Know what you're dealing with.* You may be afraid of contracting AIDS from being near the person. Given the amount of misinformation and hostility that has surrounded AIDS, this fear is understandable.

You have nothing to fear, however, from being physically close to a person with AIDS—from sitting in the same room, from eating dinner with that person, from touching or hugging him or her. The AIDS virus is not airborne; it is transmittable only by direct contact with an infected person's bodily fluids, notably blood and semen.

Admit that you're scared. Trying to mask the fear will not work, as your loved one will pick up your nonverbal signals. Talking about the fear with an informed health care professional, a trusted friend, or a counselor will go a long way toward alleviating it.

■ *Be honest about whatever prejudices*

you might have about AIDS. Perhaps your loved one with AIDS is homosexual, or contracted the disease through IV drug use. Whatever your feelings about homosexuality or drug use, remember that AIDS is a disease, not a moral issue. And it is an indiscriminate disease. AIDS can, and does, strike people without regard to age, background, or life-style.

Try to look beyond the illness itself and the way the person may have contracted it. See the human being behind the disease. This may help you overcome, or at least set aside, any prejudices you have surrounding AIDS.

■ *Confront your own fear of death.* Often what makes us most uncomfortable about being with a terminally ill person is not his or her impending death, but our own! AIDS forces us to confront not only the eventuality of our loved one's death, but our own mortality. As has been said, "None of us gets out of this alive." In a death-denying culture such as ours, we are uncomfortable being reminded of this fact. But if you are honest about your own fear of the journey toward diminishment and death, you'll be more at peace in the presence of someone who just happens to be a little farther along on the journey.

■ *Allow yourself to grieve.* "When I learned he had AIDS, I was angry," says Tammie Long, close friend of a person with

If there is no ready answer, no logical explanation for the pain of those dying, for the fear of those who are ill, for the grief of those left behind—if there is no answer, there is for us assuredly a response.

We must love each other through this, for if compassion is not the most human of responses, then there is no hope. We must love each other through this, because all we have is each other.

—John E. Fortunato
AIDS, The Spiritual Dilemma

AIDS. "Then I tried to deny it. Then I bargained with God. I realized I had to go through all the stages of grief, just as he did."

"We are all falling. This hand's falling too—/all have this falling sickness, none withstands./And yet there's always One whose gentle hands/this universal falling can't fall through."

—Rainer Maria Rilke

Especially if you are a caregiver to the person with AIDS, you can easily forget to pay attention to your own feelings. When someone you love hurts, it's natural for you to hurt, too. If you put all your energy into trying to "be strong," even when you feel anything but strong, you will not have much energy left to help the person you love.

Find a healthy way to give expression to your grief. This means looking for someone other than the person with AIDS to help you through your sorrow. Don't overlook the strength and encouragement that can come from trusted friends or a support group. And don't expect to walk through the stages of grief in nice tidy steps. Grieving, like most of human life, is a messy business. But if you permit yourself to experience your feelings fully, however uncomfortable that might be at the moment, you will heal.

■ *Be there for your loved one.* "If a friend

calls to say hello, it means a lot to me—just knowing that person is thinking of me,” says Harry Bryson, who learned he had AIDS nearly two years ago.

People with AIDS often experience deep isolation. Because of the stigma that continues to surround the disease, many persons with AIDS are still shunned, not only by some in the health care professions, but by their own loved ones.

Being there for your loved one isn't a question of time, nor of simply being there physically. It's a matter of being a gentle and healing presence. If you are dealing honestly with your own fears and prejudices and grief, you will be that kind of companion.

Being there doesn't mean fussing over the person like a mother hen either. “The one thing I did not do with Freddie,” says Pat Greene, “was tell him, ‘You should rest more, you should eat more, you shouldn't be going out.’ I knew that he needed to live the time he had to the fullest, and he did.”

■ **Let go.** This may be the hardest part, but also the most essential. Letting go does not mean abandoning your loved one. It means realizing that his or her life—ultimately all life—is not ours to control. You can't “save” your loved one from AIDS. You can be a source of strength, comfort, and hope, but

*Only for a short time have you
loaned us to each other. Be-
cause you take form in your
act of drawing us, and we take
life in your painting us, and
we breathe in your singing us.
But only for a short time have
you loaned us to each other.
Because even a drawing cut in
crystalline obsidian fades. And
even the green feathers, the
crown feathers, of the Quetzal
bird lose their color, and even
the sounds of the waterfall die
out in the dry season. So, we
too, because only for a short
time have you loaned us to
each other.*

—Aztec prayer

you can't "fix things" or control the illness.

"I had to let go of my need for him to be well," says Cathy Hawes, who lost a loved one to AIDS a year ago. "I realized that my need to see him well was forcing him to hide his illness from me. He tried to deny what was going on in his body because he didn't want those closest to him to feel the pain."

Letting go becomes possible when you believe your loved one ultimately belongs to another, Higher Power. Turning the person over to the care of God through prayer is a step that can bring profound peace, and leave you free to be a tender companion while your loved one is still with you.

■ ***Be grateful.*** For AIDS? No. AIDS is a devastating disease that we must fight with all the resources at our disposal. But blessings are hidden

Sources of additional help

Books: *The Color of Light: Meditations for All of Us Living With AIDS* by Perry Tillerias, Minneapolis, Minnesota, Harper/Hazelden, 1988. *Prayer Journey for Persons With AIDS* by Robert Nugent, St. Anthony Messenger Press, Cincinnati, Ohio, 1989. *Voices of Strength and Hope for a Friend With AIDS* by Joseph Gallagher, Kansas City, Missouri, Sheed & Ward, 1987 (tape, English and Spanish editions, Kansas City, Missouri, Credence Cassettes). *AIDS, The Spiritual Dilemma* by John E. Fortunato, San Francisco, California, Harper & Row, 1987. *An Epistle of Comfort* by William Josef Dobbels, S.J., Kansas City, Missouri, Sheed & Ward, 1990.

Articles: "A Promise Kept" by Barbara L. Hernandez, *Bereavement Magazine*, September 1990. "One of Us" by Jeffrey P. Hiles, *Saints Herald*, February 1990. "Love Is for Giving" by Deloris Kinnard, *The Greater Kansas City HIV/AIDS Update*, The AIDS Council of Kansas City, November 1990.

Organization: AIDS Pastoral Care Network, 2913 N. Commonwealth, Chicago, IL 60657. If you are unable to locate an AIDS service organization in your area, call the National AIDS Information Clearinghouse: (800) 458-5231.

in this curse if we look for them.

"People with AIDS can teach us how to live life at its core," says Tammie Long. "The greatest gift I have received is a heightened awareness of the value of daily life," says Cathy Hawes. "Freddie's death was also God's invitation to me to go out and serve other people with AIDS," says Pat Greene. "I feel blessed—I truly do," says Harry Bryson. "I look at life differently now. I'm able to forgive, I'm able to mend fences. I've learned so much about myself. Each day is a healing because I've lived another day. And when the time comes for me to die, that will be a healing too."

Take heart

As you walk the path of AIDS with your loved one, be aware of all that person is teaching you. About death. About life. About human companionship and compassion. And, most of all, about faith and hope. Not hope for a miracle cure, though all of us wait for the day when AIDS is overcome. But, rather, faith in the purpose and dignity of life on earth—however long or brief—and faith that if this life has such meaning, what comes after this life will be infinitely more rewarding.

If you are able to experience some of the blessings buried within the grief and pain of AIDS, you will realize that when someone you love has AIDS, it is the love, and not the disease, that conquers in the end. ■

Dan Grippo is a writer and publishing consultant. He is vice president of the board of directors of Good Samaritan Project, a Kansas City AIDS service organization.

CareNotesTM

21207-6



Abbey Press
St. Meinrad, IN 47577

50-21207-6. This publication is recyclable and printed on recycled paper.

Address correspondence to:

One Caring Place, Abbey Press, St. Meinrad, IN 47577.

Cover photograph by © Neena M. Wilmot-STOCK/ART IMAGES

© 1991, St. Meinrad Archabbey, St. Meinrad, IN 47577. No portion of this publication may be reproduced without permission from the publisher.

*Strength and help
for a friend*

CareNotes
TAKE ONE - and take heart.
GIVE ONE - and give hope.

Feeling the Loneliness of Illness

by Marianna Kane Neal

The day I found out I had cancer, I felt utterly alone. Nothing anyone said really mattered. God seemed to have deserted me. In the days that followed, I realized I was lonelier than I had ever been in my life.

Sometimes I wanted to talk with someone who had been through the same feelings. But I didn't even know a breast cancer survivor. I felt completely isolat-



ed, numb one minute and in tears the next. Although prayer had always been a part of my life, the words simply wouldn't come. Where was prayer when I needed it the most? Why, when I reached within, did I find nothing?

Working your way through

No matter how devoted your friends or relatives may be, illness can make you vulnerable to over-

whelming loneliness. Yet you can use your loneliness to learn much about who you are and what is really valuable in your life. And you can find your way to God, who will give you peace and companionship. Let me share with you some suggestions that may bring you solace in the loneliness of illness.

■ ***Use your illness—instead of being used by it.*** In the confinement of illness, many feelings surface. You may regret not having taken better care of yourself or not having sought medical help sooner. You may remember wasted time and times of failure.

Be gentle with yourself. Allow yourself to feel what you feel without judging yourself or becoming guilty. Remember, your illness isn't a punishment for anything you have done. Reach within yourself, past the anger, the pain, and the guilt to the center of yourself that is whole and holy.

Then try to come to terms with what is happening in your life. As you explore your fears and losses, see your illness as an opportunity to get to know yourself better than you ever have before.

Consider it a chance to appreciate yourself as you really are, without the masks or pretenses you may feel you need to adopt in the course of "normal" living. Consider it a chance to realize what is truly valuable in your life.

My loneliness, for example, taught me that I could care for others as a hospital minister. Before my illness I never would have even considered visiting anyone in a hospital unless I absolutely had to. Working through my own cancer and the feelings surrounding it made me more sensitive to others who are suffering.

■ ***Find sources of support.*** Expressing your pain to others can provide tremendous relief. Look into joining a support group for people with your illness. Once you are ready to talk to someone, such a group can truly be a blessing, helping you cope not only with your illness but also with the accompanying loneliness. There you can meet people who are experiencing what you are and who understand your feelings.

If you are not able to go to a meeting, ask if a member could come and visit with you. (To locate a support group, try the phone book or library or ask your doctor, hospital staff, or clergy-person.)

If you feel like reading, a library or bookstore can recommend some excellent books. As I read books on cancer, I found it comforting to realize how many other people had felt the same way I did. Books and support groups helped me to know that I was not alone.

Illness takes away parts of your life, but in doing so it gives you the opportunity to choose the life you will lead, as opposed to living out the one you have simply accumulated over the years.

—Arthur W. Frank
Reflections on Illness

■ ***Reach out to others.*** When talking to your loved ones about your illness, you will have to decide how much they really want to know and can handle. Then take time to listen to them, their plans, their ideas, their daily tasks.

“Many claim that the quiet hours of illness introduced themselves to their true selves.”

—Mildred Tengbom, *Why Waste Your Illness?*

Stay interested in what is happening in the lives of those you love. When you have the energy, call or write them short notes to let them know you’re thinking about them. Try not to dwell on yourself and your problems but on others and their interests. If your friends sense you are truly interested in them, they will visit you more often. Ask them for advice on decisions you have to make. They will know you value them and their opinions.

Reading or watching the news, TV, or movies will give you a variety of subjects to discuss when people visit. You need not feel you have to “entertain” your visitors, but you *can* take the focus off your illness.

■ ***Accept whatever others are able to offer.*** You may find that people will avoid you, not because they want to but because they are uncomfortable around illness and don’t know what to say.

Two months before he died of cancer, actor Michael Landon was on *The Tonight Show Starring*

Johnny Carson. Landon talked positively about his life, how important small events had become, and the therapeutic value of laughter. Carson confessed that he had been unsure of what to say to Landon, knowing that he was probably dying. But, he added, Landon's positive attitude had made talking with him much easier and even enjoyable.

If you would like to talk with someone you know is unable to face you, perhaps a short, positive note or call will ease the awkwardness. Accept people for who they are and whatever they are able to give in this difficult situation, but also help make it easier for them to accept who you are—illness and all.

■ *Set goals for yourself.* If you have nothing to do but feel sorry for yourself, loneliness can overpower you. Make plans every morning for living that day to the fullest. Your goals may be simply to watch the birds outside or the clouds as they journey overhead. It doesn't matter how small your goals are, as long as they help you recognize the sacredness of each moment.

Some days all I planned was to get up and fix myself a cup of tea. Another day I asked a friend to take me for some ice cream. Even though I had never painted, I decided one afternoon to get out my son's water colors and paint a "picture" of my life in different colors and designs. It was relaxing, revealing, and comforting. Laughing later on at my "masterpiece" was great therapy, as was sharing my painting with other people.

To heal is to trust in a creative force that is loving and forgiving, and to know in our hearts that there is no separation and we are all joined in love with God and each other.

—Gerald Jampolsky,
"Living and Loving One
Second at a Time,"
Healers on Healing

Another goal might be to keep a journal. Sometimes I wrote in my journal about how I was feeling. I had pages for writing down questions that I wanted to ask visitors or doctors. I kept grocery lists and lists of things I wanted to remember to do.

I have an aunt in her 80's who has been writing for several years about her childhood. Whenever she remembers an event, she writes it down. She says she is amazed how one event leads to another that she had previously forgotten. She relives and shares these memories with her children, grandchildren, and great-grandchildren. It's her gift to them that has grown out of her times of loneliness.

■ ***Rely on prayer.*** The psalms speak of loneliness, trusting God, and turning to God for support. Read them meditatively for inspiration and comfort. There are also some excellent religious records and tapes. Their lyrics helped me pray or prayed "for" me when words wouldn't come. I found them particularly helpful when I was in pain, depressed, or just too tired to pray.

If you feel well enough, call your church and offer to pray for the special needs of members of your congregation. My parish priests would call or stop by to tell me about parishioners who needed my prayers. This made me feel that I really was an important part of the community, even though I wasn't able to attend services. And

Sources of additional help

Books: *Anatomy of an Illness as Perceived by the Patient* by Norman Cousins, New York, New York, Bantam, 1983. *Getting Well Again* by O. Carl Simonton, M.D., Stephanie Matthews-Simonton, and James L. Creighton, New York, New York, Bantam, 1982. *Peace, Love and Healing* by Bernie S. Siegel, M.D., New York, New York, Harper & Row, 1989.

knowing about others who were hurting helped me focus less on my own loneliness and pain.

Don't be afraid to ask others to pray for you. If you are comfortable with it, you might even ask them to pray with you. This can be a very moving and powerful experience as you become united in prayer.

Tell God exactly how you feel—your fears and doubts and pain. Ask for the strength to fill each day doing whatever God wants you to do. Then relax and allow God to lead you “beside the still waters.”

Take heart

The loneliness that comes with illness can threaten to swallow you up in its darkness. Until I accepted my feelings about being ill and was able to reach out

to others in friendship and concern, I felt as if I were stagnating and useless. My little daily accomplishments helped me make sense out of what at first had seemed beyond hope.

Writer Flannery O'Connor once said that illness “is a place where there's no company, where nobody can follow.” It also can be a place of learning and acceptance, a place where you can find strength. This strength will help you to lead yourself and others to peace as you place your faith in a loving God who is always with you. ■

Marianna Kane Neal is a wife, mother, high school teacher, and volunteer hospital minister. She has written for several publications and recently completed two books that she hopes to publish.

CareNotesTM

21230-8



Abbey Press
St. Meinrad, IN 47577

50-21230-8. This publication is recyclable and printed on recycled paper.

Address correspondence to:

One Caring Place, Abbey Press, St. Meinrad, IN 47577.

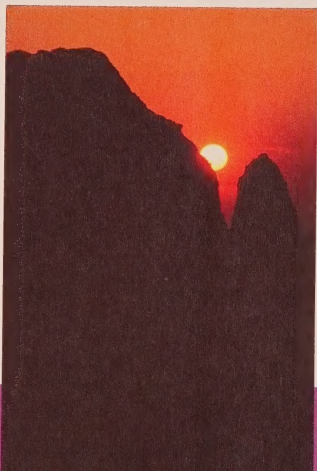
Cover photograph by © Neena M. Wilmot-STOCK/ART IMAGES

© 1992, St. Meinrad Archabbey, St. Meinrad, IN 47577. No portion of this publication may be reproduced without permission from the publisher.

Hanging on to Hope Through a Serious Illness

by Hirshel Jaffe

In 1978, I bounded energetically across the finish line of the New York City Marathon wearing a T-shirt proclaiming me "The Run-



ning Rabbi." I was just as tireless in my calling as a rabbi. I'd never been sick in my life. I felt indestructible. That was then.

Just six years later my illusion was shattered as I lay dying of hairy-cell leukemia. Despite three surgeries and chemotherapy, my blood counts were plummeting, the leukemia had almost destroyed my immune system, and my body was ravaged from weeks of high fevers. My last hope was the experimental drug interferon. The interferon saved my life. Today my bone marrow shows virtually no traces of cancer.

Working your way through

For over 20 years as a rabbi, before my illness, I had helped others through crisis. I was supposed to have all the answers. Yet when I got sick, I discovered I didn't have them. I felt confused, frightened, and desperate. My experience with serious illness has

How to Live With Illness

1. *Talk about the illness.*
2. *Accept death as part of life.*
3. *Consider each day as another day of life, a gift from God.*
4. *Realize that life is never going to be perfect.*
5. *Pray! It isn't a sign of weakness. It is your strength.*
6. *Learn to live with your illness instead of considering yourself dying from it.*
7. *Put your friends and relatives at ease yourself.*
8. *Make all practical arrangements for funerals, wills, etc.*
9. *Set new goals; realize your limitations. The simple things can be the most enjoyable.*
10. *Discuss your problems with your family as they occur.*

—Orville Kelly, founder,
Make Today Count

made me want to share with you what I've learned.

"Survivors are people who move purposefully toward either resolution or acceptance."

—Robert Veninga, *A Gift of Hope*

■ ***Cheer yourself on.*** Ultimately you must learn to comfort yourself. Be kind to yourself. Learn to laugh at yourself and enjoy life. Don't think of yourself as worthless or worth less because you've been stricken. Don't be passive about your treatment or afraid to tell your doctors your needs.

Don't feel guilty if you're too sick to do things. You have value simply because you are, even if you cannot be "productive" in the way to which you were accustomed.

■ ***Set goals for yourself.*** No matter how small, any goal helps you feel a

sense of achievement. Watch your daughters iceskate, go out with your friends, put pictures in an album. Keep up interest in your life projects. Do for others; it will help you to feel alive and regain self-esteem.

Even if you have just five good minutes a day, use that time and build on it. If physical limitations prevent you from doing tasks in your usual way, try to devise new ways to do them.

■ *Be thankful for each day and greet it joyously.* Live life to the fullest. How long you live is not as im-

Trust in God's care enables a person to relax into God's hands, and gives one a sense of being one with God, at one with the only power capable of reaching through distance or delirium, the only power capable of making some good out of our own helplessness and inadequacy.

—Leonard Bowman
The Importance of Being Sick

portant as what you do with your time, or what you are in that time.

Today I know what's really important in my life—being with the ones I love. And I make a point of telling these people often how I feel about them. Accept the comfort offered to you by friends and family. It's not a sign of weakness to allow them to do what they can to make things easier for you.

■ *Turn to your faith.* Since my illness, I've become more open to possibilities about God. Of course, I feel sheepish that I had to get sick before I took this more seriously. I guess we don't think we need God until we run into trouble.

My concept of God is now much different. I've learned how vulnerable we are, how our lives are in God's hands. When I was so ill, I discovered a personal God, and I began to ask God to help me and hold me and see me

through—to surround me with comforting and strengthening love.

Take heart

By facing death I learned how to live. My illness taught me the real meaning of being a rabbi. It's not who can be the best scholar; it's who can touch people. I used to be too "hyper," the running rabbi, breezing by people. Now I take time to talk and listen more deeply. I know what it's like to hurt. I understand people's fears, and can now begin to reassure them out of my own struggle.

We can find meaning and hope even in our darkest days. You didn't ask for this painful experience, but you can choose your response to it. You can choose to grow from it, and you can choose to shape it into a positive force in your life. ■

CareNotesTM

LARGE PRINT EDITION

24006-9



Abbey Press
St. Meinrad, IN 47577

50-24006-9. This publication is recyclable and printed on recycled paper.

Address correspondence to:

One Caring Place, Abbey Press, St. Meinrad, IN 47577.

Cover photograph by Cleo Photography

© 1991, St. Meinrad Archabbey, St. Meinrad, IN 47577. No portion of this publication may be reproduced without permission from the publisher.

A COMMITMENT ON HIV/AIDS BY PEOPLE OF FAITH... *THE COUNCIL CALL*



A COMMITMENT ON HIV/AIDS BY PEOPLE OF FAITH . . . *THE COUNCIL CALL*

We are members of different faith communities called by God to affirm a life of hope and healing in the midst of HIV/AIDS. The enormity of the pandemic itself has compelled us to join forces despite our differences of belief. Our traditions call us to embody and proclaim hope, and to celebrate life and healing in the midst of suffering.

AIDS is an affliction of the whole human family, a condition in which we all participate. It is a scandal that many people suffer and grieve in secret. We seek hope amidst the moral and medical tragedies of this pandemic in order to pass on hope for generations to come.

We recognize the fact that there have been barriers among us based on religion, race, class, age, nationality, physical ability, gender and sexual orientation which have generated fear, persecution and even violence. We call upon all sectors of our society, particularly our faith communities, to adopt as highest priority the confrontation of racism, classism, ageism, sexism, and homophobia.

As long as one member of the human family is afflicted, we all suffer. In that spirit, we declare our response to the AIDS pandemic:

1. ***We are called to love:*** God does not punish with sickness or disease but is present together with us as the source of our strength, courage and hope. The God of our understanding is, in fact, greater than AIDS.
2. ***We are called to compassionate care:*** We must assure that all who are affected by the pandemic [regardless of religion, race, class, age, nationality, physical ability, gender or sexual orientation] will have access to compassionate, non-judgmental care, respect, support and assistance.
3. ***We are called to witness and do justice:*** We are committed to transform public attitudes and policies, supporting the enforcement of all local and federal laws to protect the civil liberties of all persons with AIDS and other disabilities. We further commit to speak publicly about AIDS prevention and compassion for all people.
4. ***We promote prevention:*** Within the context of our respective faiths, we encourage accurate and comprehensive information for the public regarding HIV transmission and means of prevention. We vow to develop comprehensive AIDS prevention programs for our youth and adults.
5. ***We acknowledge that we are a global community:*** While the scourge of AIDS is devastating to the United States, it is much greater in magnitude in other parts of the world community. We recognize our responsibility to encourage AIDS education and prevention policies, especially in the global religious programs we support.
6. ***We deplore the sins of intolerance and bigotry:*** AIDS is not a 'gay' disease. It affects men, women and children of all races. We reject the intolerance and bigotry that have caused many to deflect their energy, blame those infected, and become preoccupied with issues of sexuality, worthiness, class status, or chemical dependency.
7. ***We challenge our society:*** Because economic disparity and poverty are major contributing factors in the AIDS pandemic and barriers to prevention and treatment, we call upon all sectors of society to seek ways of eliminating poverty in a commitment to a future of hope and security.
8. ***We are committed to action:*** We will seek ways, individually and within our faith communities, to respond to the needs around us.

Portions of the text of this document were taken, with permission, from "The African American Clergy's Declaration of War on HIV/AIDS," (The Balm in Gilead Inc., 1994), and from "The Atlanta Declaration," (AIDS National Interfaith Network, 1989).

Yes! I/We support a compassionate and just response to HIV/AIDS.

Please fill out the information below, detach, place in an envelope, and mail to:

UNITED METHODIST HIV/AIDS NETWORK
C/O HEALTH AND WELFARE MINISTRIES PROGRAM DEPARTMENT
GENERAL BOARD OF GLOBAL MINISTRIES
475 RIVERSIDE DRIVE, ROOM 350
NEW YORK, NY 10115

PHONE: 212-870-3909 FAX: 212-749-2641



This is an individual endorsement.



This is an organizational endorsement

Name _____

Organization _____

Address _____

City _____ State _____ Zip _____

Phone _____ Fax _____

ENDORSEMENTS

- AIDS Ministry Network - Christian Church (DOC)
- American Friends Service Committee
- Friends Committee on National Legislation
- Dr. Robert Glover, Rev. Jane Lawrence, Homeland Ministries, Christian Church (Disciples of Christ)
- Jane Hull Harvey, Assistant General Secretary, General Board of Church and Society, The United Methodist Church
- Dr. Jon Lacey, AIDS Ministry Network, Christian Church (Disciples of Christ)
- Lutheran AIDS Network
- National Catholic AIDS Network
- National Episcopal AIDS Coalition
- Office of Governmental Relations, National Ministries, American Baptist Churches USA
- Presbyterian AIDS Network
- 206th General Assembly (1994), Presbyterian Church (USA)
- Union of American Hebrew Congregations/Central Conference of American Rabbis AIDS Committee
- Unitarian Universalist Association, John A. Buehrens, President
- United Church AIDS Network
- United Methodist HIV/AIDS Ministries Network
- Universal Fellowship of Metropolitan Community Churches AIDS Ministry
- Washington Office, Unitarian Universalist Association, Robert Z. Alperm, Director
- Washington Office, Presbyterian Church (USA)
- *and others*

A Commitment on HIV/AIDS by People of Faith, *The Council Call*, was written by the Council of NATIONAL RELIGIOUS AIDS NETWORKS. The Council, a project of AIDS National Interfaith Network (ANIN), is composed of leaders of AIDS networks associated with specific national religious bodies. It is a voluntary association working together to support ANIN's mission, to foster better communication, and to enhance the dissemination of information from ANIN and/or other organizations to the individual members of the networks.

In observance of World AIDS Day, Thursday, December 1, 1994, ANIN is calling upon:

- ✓ all people of faith to "sign on" to this document, *The Council Call*, and
- ✓ all houses of worship to ring their bells 14 times at 1:40 PM local time on Thursday, December 1, 1994 in recognition of the 14 years of the HIV/AIDS pandemic.

This Document
May Be
Photocopied.

For additional copies of The Council Call or for more information about the ringing of bells or AIDS National Interfaith Network, please call ANIN at 202-546-0807.

HIV / AIDS MINISTRIES NETWORK

FOCUS PAPER # 25

A NETWORK OF UNITED METHODISTS AND OTHERS WHO
CARE ABOUT THE GLOBAL HIV/AIDS PANDEMIC AND
THOSE WHOSE LIVES HAVE BEEN TOUCHED

IN FOCUS PAPER # 25

About This Issue cover

"FACING THE GLOBAL HIV/AIDS
PANDEMIC" 3
by Rev. Charles Camahan

"I WEAR A RED RIBBON" 7
by Debbi Hood Johnson

"THEORIES OF THE EARTH" 9
by Emily Newland

"THE FACE OF AIDS:
A WORSHIP SERVICE FOR
WORLD AIDS DAY" 10
by Rev. Nancy Carter

INVITATION FOR SUBMISSIONS 13

"WORLD AIDS DAY 1994"
- Toll Church Bells 14 Times 14
- A Commitment on HIV/AIDS By
People of Faith..*The Council Call* 14

ABOUT THIS ISSUE

October 1994

Dear Network Members:

This edition of the *HIV/AIDS Ministries Network Focus Paper* focuses on World AIDS Day 1994. The emphasis of World AIDS Day this year is *AIDS and the Family*. All families, traditional and non-traditional, have important roles to play in addressing the issues related to HIV/AIDS.

Focus Paper #25 provides material that can be used in developing World AIDS Day programs and activities. *The Global HIV/AIDS Pandemic* is an edited version of a presentation I have used on several occasions to address the global context of HIV disease. One of the most important points that I try to communicate is that HIV/AIDS must be approached in the broad context of international health. Within that context, HIV/AIDS must be addressed or it will do us little good to address other health issues.

HIV/AIDS Ministries Network Focus Papers are a publication of the Health and Welfare Ministries Program Department, General Board of Global Ministries, The United Methodist Church, Room 350, 475 Riverside Drive, New York, NY 10115. Phone: 212-870-3909. FAX: 212-749-2641. Focus Papers, unless otherwise noted, may be quoted, reproduced and distributed with credit being given to Health and Welfare Ministries Program Department and the authors.

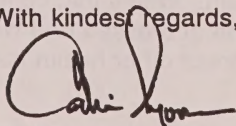
The article in the **Family Network** section, *I Wear A Red Ribbon*, by Debbi Hood Johnson shows how pain can be channeled into providing hope for others. Debbi's explanation for wearing the red ribbon calls us all to re-examine our faith and its witness in the face of this ever-growing world-wide epidemic.

The Reverend Nancy Carter has developed a worship service for World AIDS Day that can be used in your church. It is designed to draw attention to the individuals behind the statistics through the use of the idea of the faces of AIDS. It can be used in conjunction with Debbi Hood Johnson's article. *Theories of the Earth* by Emily Newland, is a poem that could also be included in your World AIDS Day activities.

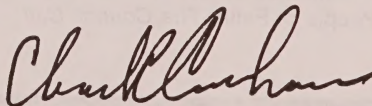
Special World AIDS Day resources are included in this edition of the **Focus Paper**. The Council of Religious AIDS Networks and the AIDS National Interfaith Network are requesting religious communities and individuals to participate in activities to draw attention to the compassion, support and hope available through faith communities. In particular, religious congregations are being asked to ring their bells 14 times at 1:40pm local time on December 1. Also, individuals, congregations and organizations are being asked to sign on to **A Commitment on HIV/AIDS by People of Faith...The Council Call**. (One copy is included in this mailing which can be copied and distributed widely.)

CAM continues to be a major resource for those affected by HIV/AIDS, with more than 450 users. If you haven't done so, we invite you to try it by using your computer and modem to dial 1-212-222-2135.

With kindest regards,



Cathie Lyons
Associate General Secretary



Charles R. Carnahan
Executive for HIV/AIDS Ministries

FACING THE GLOBAL HIV/AIDS PANDEMIC

by Charles R. Carnahan

The Reverend Charles R. Carnahan is executive secretary for HIV/AIDS Ministries in the Health and Welfare Ministries Program Department of the General Board of Global Ministries of The United Methodist Church. He has written several articles on HIV and the church and conducted numerous workshops nationally and internationally.

- **BETWEEN 30 TO 110 MILLION PEOPLE AROUND THE WORLD WILL BE INFECTED WITH HIV BY THE YEAR 2000**
- **10 MILLION CHILDREN WILL BE ORPHANED BY THE YEAR 2000 AS A RESULT OF AIDS**
- **IN AFRICA, GAINS IN CHILD SURVIVAL RATES WILL BE DECREASED, POSSIBLY REVERSED**
- **APPROXIMATELY 3 MILLION PRODUCTIVE YEARS OF LIFE HAVE BEEN LOST TO DATE TO AIDS**

To write about the global impact of HIV disease can be a daunting exercise. More has been written concerning HIV/AIDS in its brief but brutal 12 years of diagnosis than any other health crisis of modern times. Much of our world seems to be on "information overload."

The seriousness of this pandemic (worldwide epidemic) is clear. If current trends continue, HIV disease will become, within the next 7 to 10 years, the most devastating **preventable** health crisis the world has ever witnessed. While some churches have made great strides in responding to AIDS, responses of churches overall have not matched the significance of the crisis. Unfortunately, in many areas of the

world, including the United States, the church has been one of the greater hindrances to providing comprehensive prevention information and services.

As we move into the second decade of this pandemic, we have already learned that every sector of society, including the religious community (**especially the religious community**), must resolve to dedicate its resources in amounts and ways which are proportionate to the actual and potential devastation of HIV/AIDS on individuals and the global community.

Several years ago, I was part of the founding meeting of the AIDS National Interfaith Network. At that time the majority of voices heard from the religious community categorized AIDS as the "gay plague," as judgment from God. These voices offered not a God of love, but one of isolation and hatred. At that meeting, one of the participants commented that he was not surprised by the churches' response to the AIDS pandemic. He observed that "the Church has, throughout its history, had problems dealing with issues associated with semen and blood." Unfortunately both semen and blood are vehicles for the transmission of HIV.

The tables on page 6 shows the latest statistics released by the World Health Organization (W.H.O.) and the Centers for Disease Control. These figures, which record the cumulative reported deaths from AIDS in the world and in the U.S.A., just begin to tell the story of the impact of AIDS. AIDS is affecting all areas of our lives.

There is the ever growing cost in human suffering. For example W.H.O. projects that more than 10 million children worldwide will be orphaned by the year 2000. In Africa entire families and communities are mourning the loss

of too many of their most educated young adults: their hoped-for future leaders. It is impossible to project the future cost in lost lives and human potential due to illness and death from HIV disease.

We know it could be years until infection rates peak and level out globally. In recent months, surveillance teams have witnessed an alarming increase of HIV infection in Asia. Much of Africa is already devastated by AIDS. HIV infection cannot be seen simply as an issue to be dealt with alone. It must be viewed in the larger context of related issues and concerns.

HIV/AIDS is negatively affecting the already vulnerable economies in countries in Latin America, Africa, Asia, the Caribbean, and the Pacific Islands.

The government of

Thailand projects that its Gross Domestic Product will decrease by as much as 20 percent in the next few years as a direct result of HIV disease. Economic hardship is evident in villages and cities where grandparents have been forced to take on the added financial responsibility of caring for their grandchildren. Dr. Nariman Behravesh of DRI/McGraw-Hill, presenting information on the economic impact of HIV disease at the National Leadership Coalition on AIDS briefing in Washington, DC, in 1992 pointed to a reduction in worldwide Gross Domestic Product as a result of HIV disease by the year 2000 of between \$350 and \$500 billion (or the equivalent of the economies of Australia or India).

HIV is causing a slowing and even a

reversal of many of the health gains that have been made within the developing world in the past 20 years. Marjorie Dam of W.H.O. has stated that, before AIDS, the world's average life expectancy was projected to be more than 60 years by the year 2010. As a result of AIDS, the rate may drop to as low as 48 or 50 in some parts of the world. Reduction in child mortality in Africa that had come from successful, privately funded, immunization programs has been nearly wiped out by HIV.

While HIV disease is no respecter of persons, position, or power, it continues to disproportionately affect marginalized individuals and communities throughout the world. These members of God's human family can ill afford additional burdens. In June, 1992, at the Council of Evangelical Methodist Churches in Latin

As we move into the second decade of this pandemic, the religious community must resolve to dedicate its resources in amounts and ways which are proportionate to the actual and potential devastation of HIV/AIDS on individuals and the global community.

America and General Board of Global Ministries sponsored HIV/AIDS consultation held in Recife, a Brazilian woman who worked with local sex workers spoke of her efforts to positively impact their lives and provide risk reducing HIV/AIDS education. She said, "To talk about putting oneself at risk for HIV that may impact their lives within the next 3 to 5 years, in their context is irrelevant and ineffective because daily life, itself, is a risk."

In many parts of our world, women do not possess the power to be able to make decisions concerning with whom, when, or how they have sex with a partner. The Program on Population has observed, "Poor women with low levels of education and who have little control over their sexual relationships are leading candidates to

contract AIDS. Most women are at risk not as a result of their own behavior but from that of their male sexual partners." AIDS is presently the leading cause of death in women aged 20-40 in certain cities in sub-Saharan Africa, Western Europe and the Americas. In many countries of the world, the traditions and cultural norms include practices that allow and encourage multiple sexual partners, rituals that put one at risk, and a devaluing of women preclude active choice making.

Women throughout the world, because of this devaluing, are still viewed as mere property or as utilitarian instruments by their male counterparts. To talk about HIV in a global context necessarily is to talk about the plight of women, their empowerment, and their basic human worth and dignity.

Because women are so severely affected by HIV infection, children remain vulnerable. General Board of Global Ministries missionaries and staff traveling in Africa report that, upon entering villages, they look around and see old people and young children. When they inquire where the children's parents are, they are told that they have died of "slims disease" (a term frequently used in Africa to refer to AIDS). Millions of children are growing up without parents to care for them. At early ages they have to take on roles that are usually reserved for much later in life.

AIDS has increased sexual abuse of children. In some parts of the world, young girls and boys 10 to 12 years old, some younger, are kidnapped or sold to the sex trade industry. Such children command high prices in sex trade houses, since customers believe someone so young is "clean" (not infected). Once they test positive, they are returned to the area from where they were kidnapped or purchased.

When the family or village discovers they are HIV positive, they are run out of the village or even killed. Troubling reports from Burma indicate that sex workers who have been returned to Burma from the sex trade houses of Thailand have been killed by the Burmese government.

HIV disease has the very real possibility of changing the course of history and development of many countries if bold action is not taken to stop its spread. The church must be equally bold in its response.

Believing there will be a vaccine or effective treatment for HIV disease only indicates our Western bias. The fact is that if an effective treatment were announced today or a vaccine developed tomorrow, at least 80% of the world would still face the effects of an AIDS epidemic. The distribution and cost of such vaccines and treatments are simply out of the reach of most severely affected countries. The estimated cost of caring for each person with AIDS in Africa ranges from \$US100 to \$US1,500. Place that against the reality that in Africa, government per capita spending on health care varies from \$US1 to \$US10 per year.

HIV disease continues to call people of faith, our institutions and governments to action to stop the spread of this disease. The reality of AIDS informs us that if we do not respond appropriately, little progress will be made in responding to most of the world's other problems. The impact of HIV cannot be ignored.

We know what we need to do to stop the spread of HIV/AIDS. Our challenge is to find the will, through our faith, to provide the education, medical and human response necessary to meet the challenges we face in this pandemic.

**AIDS Cases Reported to W.H.O. by Continent/Year
Based on Reports Received Through June 30, 1994**

NEW CASES

<i>Year</i>	<i>Africa</i>	<i>America</i>	<i>Asia</i>	<i>Europe</i>	<i>Oceania</i>	<i>TOTALS</i>
1979	0	0	0	0	0	0
1980	0	93	1	20	0	114
1981	0	322	1	29	0	352
1982	2	1156	1	95	1	1255
1983	17	3345	8	295	6	3671
1984	187	6656	8	733	79	7663
1985	512	12624	33	1874	143	15186
1986	3357	21256	81	3915	254	28863
1987	12697	34643	119	6919	417	54795
1988	22572	43970	164	9717	590	77013
1989	40637	53040	269	13073	680	107699
1990	51056	62002	447	16136	758	130399
1991	67761	73147	431	17642	866	159847
1992	56299	84918	1207	18628	811	161863
1993	73067	124592	3074	15493	723	216949
1994	3212	2013	3124	11099	2	19450
TOTALS	331376	523777	8968	115668	5330	985119

**AIDS Cases Reported to the CDC
Based on Reports Received Through December 31, 1993**

The following data are from the Centers for Disease Control (CDC) quarterly HIV/AIDS Surveillance Report.

The cumulative number of AIDS cases reported to CDC is 361,509. Adult and adolescent AIDS cases total 356,275 with 311,872 cases in males and 44,403 cases in females. Through the same time period, 5,234 AIDS cases were reported in children. The term "children" refers to persons under age 13 at the time of diagnosis.

Total deaths of person reported with AIDS are 220,871, including 218,052 adults and adolescents, and 2,819 children.

U.M. FAMILY HIV/AIDS NETWORK

A NETWORK OF UNITED METHODIST FAMILIES AND
OTHERS WHO HAVE BEEN TOUCHED BY HIV/AIDS

I Wear A Red Ribbon

by Debbi Hood Johnson

Debbi lives in Charlotte, North Carolina, where she has been an AIDS educator/counselor for eight years. She is currently writing a book about her husband and their fight against AIDS. Debbi is the daughter of a former Wesleyan Methodist minister.

People often ask me why I wear a Red Ribbon. Some people ask the question simply to find out what the ribbon means, but other people are really asking a hidden question: they wonder what experience in life has moved me so that I would want to wear a Red Ribbon, a visible reminder to all who see me of the continuing battle against HIV and AIDS. They are asking why I, a white heterosexual female in the heart of the conservative South, would choose to take an often unpopular stand, instead of quietly going about my life. Unknowingly, they are asking about my husband, BJ.

BJ made me his wife, but AIDS made me his widow. He died in my arms at 1:45 a.m. on Monday, May 17, 1993, in the little white house we had moved into only two days earlier. Surrounded by packed boxes filled with our books, our music, our photographs, and other mementos of our life together, we lay in the dark on the hospital bed provided by Hospice. Consumed, at this point, by massive brain lesions caused by PML (Progressive Multifocal Leukoencephalopathy), Beej had lapsed into a coma hours before.

Earlier that day his wonderful parents and our

supportive friends, our "family of choice," had come, encircling his bed to say their soft good-byes, kiss his cheek gently, and whisper final messages into his ears as the room began to fill with the loud, bone-chilling sound of fluid s collecting in his lungs as he struggled to breathe.

In our private final hours, I sang to him, prayed over him, and recited the 23rd Psalm over and over as I carefully brushed his long hair. I reminisced aloud about how we met and some of our favorite "heart snapshots"-- those special memories and private jokes and tender moments we had shared for so long. I chose to believe BJ could still hear me through the curtains of his coma.

As I sang one of our most special songs to him, I suddenly noticed my voice was no longer competing with the loud gurgling "death rattle" of BJ's breathing. I sat up on the bed and saw that his eyes were open-- he was looking at me. I knew he could really see me once again and that he could see that I was truly with him until the end. His face looked so serene, with a slightly lopsided grin.

"Go ahead, sweetie," I whispered hoarsely as I held him, "it's okay to let go now." As I kissed his lips for the last time and felt his life leave his body, my hand stayed on his chest, where his body heat remained the longest. I sobbed as I felt the chill spread; the warm spot over his heart grew smaller until it was no more. Another brave warrior in the fight against AIDS had fallen.

Why do I wear the Red Ribbon? I wear it because I CAN. I am still alive, still able to carry the message about the reality and urgency of AIDS and how HIV can be prevented. I carry this message for those whose voices can no longer be heard but whose presence can still be felt. What message is that? I carry the message-- to all who will hear AND listen-- that HIV/AIDS is, at this point, 100% FATAL... but it is also 100% PREVENTABLE.

I carry the message that Persons Living with AIDS (PLWAs), or-- as I heard recently from a feisty long-term survivor-- PLISOAs (Persons Living In Spite of AIDS) are PERSONS first and foremost:

- persons who have families and loved ones,
- persons who have dreams and hopes and fears,
- persons who laugh and cry,
- persons who deserve the same respect as you and I.

The gay community, for more than a decade, has shown us an incredible example of what unconditional love and honest, unflinching AIDS prevention education can accomplish. What about the rest of us? Where are the mainstream churches? I have been dismayed by stories of persons picketing AIDS funerals with hateful signs or quietly asking HIV-infected families to leave their congregations so that the tithes and offerings won't diminish.

I know that these hurtful actions are not the only witness of churches. Others have heeded Jesus' message in Matthew 25:35-45 ("...I was sick and you visited me..."). Recently I have read and been deeply touched by the document "The Council Call" that the AIDS National Interfaith Network (ANIN) has asked all persons of faith to sign on to by World AIDS Day this year. It sounds a clarion cry for all of us to serve

those in need, people who are gathering up the courage every morning to get out of bed to face yet another day with AIDS.

When I wear the Red Ribbon, I am demonstrating my compassion and care for people living with HIV/AIDS, my determination that those who have already died from AIDS-related causes will not be forgotten, my support for the ongoing efforts of all AIDS service organizations and researchers, my respect for the dedicated caregivers, and my desire to educate others about how to halt the spread of this obscene plague.

I can think of many other reasons to proudly wear the Red Ribbon, and these reasons have names and faces:

Bill, the first PLWA I knowingly met and for whom I became one of Charlotte's first volunteer AIDS Buddies;

David, the quiet man whose face had become a macabre mask of purple Kaposi's Sarcoma lesions;

Daphne, the woman who fretted about who would care for her children after she had died;

Tony, the entertainer who hung himself in desperation, afraid of how AIDS would continue to ravage his mind and body;

Curtis, the proud African American who had such a big heart and tried to alert his community to its risks before his life was cut short one Christmas;

Little Jessica, whose panel in The NAMES Project AIDS Memorial Quilt haunts me to this day with its stuffed animals and baby blanket;

Ryan White, whose unyielding courage showed the world that AIDS might sap his strength but never bend his spirit;

Ron, whose independent streak continued until he drew his last breath in his apartment, surrounded by his friends and beloved cat; and

BJ, my sweet, gentle husband, who never passed up an opportunity to speak to groups to educate them and to "put a face on AIDS." AIDS finally robbed him of his speech, his mobility, his bodily functions, his smile---but never his dignity.

There are those who believe the Red Ribbon has lost its meaning, that it's only an empty symbol now. I disagree! As long as my Red Ribbon gives someone the opportunity to ask me a question about AIDS, or gives someone the strength to go through another day encouraged by this small sign of support and solidarity, then its message is very clear:

The Red Ribbon simply means that I care.

*"Theories of the Earth"
by Emily Newland*

It remains to us now to formulate a theory
of our own lives, to excavate the layers
through which we have settled into our selves;
the drifted continents of days we might gather
into explanation, sounding our lives as seas are sounded
by the light toward which they are impelled.

We might see what it is we are surviving,
and from what we are resulting, we who have measured
our fevers against the suns, we who have named our selves
with the names of every heaven. Will we pass now
from the classified globe, whose atmospheres have fallen
onto the heads of saints?

And what will we say to the arrogance of mountains
who infinitely continue expecting everything
and who are certain, as they watch us going,
that they, alone, endure?

*From In Memoriam: Everybody, an unpublished book in progress, by
Emily Newland, Copyright 1994. Used by permission.*

*Emily Newland's poetry and short stories have been published in
magazines and journals such as The Missouri Review, Light, Ellery
Queen Mystery Magazine, Twilight Zone Magazine, and Roz
Warren's humor anthologies. She has a fellowship in short fiction
from the Arkansas Council for the Arts and Humanities.*

The Face of AIDS A Worship Service for World AIDS Day

By Nancy A. Carter

Nancy A. Carter is a consultant for the Health and Welfare Ministries Program Department, General Board of Global Ministries, The United Methodist Church.

This service has been designed for use with "I Wear a Red Ribbon" by Debbi Hood Johnson and other materials in this month's mailing. Feel free to adapt these resources to your needs.

Hymn: "Lord, Whose Love Through Humble Service," #581, *The United Methodist Hymnal*

Reader 1: 1994 is the International Year of the Family. As the year began, the General Assembly of the United Nations heard a warning from Donna Shalala, Secretary for Health and Human Resources for the United States. She said that families worldwide are being torn apart from the force of the AIDS epidemic. HIV is striking increasing numbers of children and adolescents and destroying family ties at a time when the world is struggling to preserve them.

Reader 2: The World Health Organization has made some mind-boggling projections about the spread of AIDS. It predicts that by the year 2000:

- 30-40 million people in the world will have been infected with HIV; 8 million of these people will have died already;
- 90% of the new infections will be happening in two-thirds world countries, primarily through heterosexual sex;
- 10 million children and teens will have been orphaned by the AIDS pandemic;
- 10 million babies will have been born with HIV antibodies in their blood;
- 13 million women will have been infected.

R1: The World Health Organization believes that, in the decades after the year 2000, more than 1 billion people-- 1/5th of the world's population-- could be infected with HIV.

Facts and projections are important. They help us to understand what is happening today and what could happen tomorrow. They help us to make decisions about what we will do, as Christians striving to be faithful to God.

R2: Even more important than statistics are the people themselves. Jesus stressed this truth with his face-to-face personal ministry with people. He also taught that his followers must do good and love God, others, and self in order to be recognized as the righteous ones of God. In the parable of the sheep and the goats in the Gospel of Matthew, Jesus says that both the just and the unjust ask, "Lord, when did we see thee hungry, thirsty, naked, sick...?"

(Read Matthew 25:34-40.)

Reading: "I Wear a Red Ribbon" by Debbi Hood Johnson

Hymn: "Help Us Accept Each Other," #560, *The United Methodist Hymnal*

R1: We have heard the words from the Gospel of Matthew about when we have visited with the Christ. We have heard Jesus' words illustrated in Debbi Hood Johnson's witness, "I Wear a Red Ribbon." Let us be in an attitude of meditation, close our eyes, become quiet, look, and listen inwardly. (*speak slowly and quietly*)

Take some time now to go in your mind's eye to a safe and comfortable place. Relax there. (*pause*)

Reflect on the ways the Christ has appeared to you in your life. (*pause*)

Can you see the face of the Christ? What does it look like? (*pause*)

How do you respond to the face of Christ? (*pause*)

Now look again. Can you see in Christ's face the many faces of people with AIDS? (*pause*)

Can you see the HIV positive women, men, teenagers, girls, boys, babies? (*pause*)

People from all races and continents? (*pause*)

People from all economic backgrounds? (*pause*)

People from cities, suburbs, and the countryside? (*pause*)

How do you respond to the face of Christ? (*pause*)

What do you do? (*pause*)

What do you say? (*pause*)

What does Christ do or say? (*pause*)

Say goodbye now to Christ, saying any final words that you wish. Your good bye may take the form of a thank you or a promise. Do whatever is comfortable for you. (*pause*)

R2: Let us pray. Perhaps as you were looking at the face of Christ, thoughts came to your mind of persons for whom you would like to pray. Now is a time you can speak your prayers out loud and pray silently to yourself. Remember to respect the confidentiality of any who may have requested this.

(accept prayers from the group and then pray)

May we see the face of Christ in all of the family of God. May people with HIV/AIDS know the love and acceptance Jesus has shown us and not be shunned by family, friends, and community. May persons with AIDS and their loved ones experience God's grace, not guilt and blame. May they be lifted up by the Holy Spirit of God, not pulled down by the weight of sickness, poverty, oppression, or depression. May all of us in this room, whether HIV positive or HIV negative, respond to God's call in our lives and show God's love and justice in our actions. Amen

R1: Jesus calls us to follow him. We have heard stories from the Bible of how he ministered with all in need and called us to do the same. Let us show our commitment to stand with persons who are HIV positive and their loved ones:

(Choose one or more options at this time: (1) Pass an offering plate around the group, inviting those who wish to take a red ribbon and wear it to symbolize that they care; (2) Read "The Council Call"; (3) Read "A Covenant to Care"; Pass an offering plate with a request that persons give money toward The

United Methodist Church's Advance Special "Enabling AIDS Ministries" [Advance #982215-6] or another HIV/AIDS Ministry Program.)*

R2: Let us pray:

GROUP: WE ASK FOR GOD'S GUIDANCE THAT WE MIGHT RESPOND IN WAYS THAT BEAR WITNESS ALWAYS TO JESUS' OWN COMPASSIONATE MINISTRY OF HEALING AND RECONCILIATION; AND THAT TO THIS END WE MIGHT LOVE ONE ANOTHER AND CARE FOR ONE ANOTHER WITH THE SAME UNMEASURED AND UNCONDITIONAL LOVE THAT JESUS EMBODIED.

Hymn: "Love Divine, All Loves Excelling," #384, *The United Methodist Hymnal*

R2: We go assured that nothing can separate us from the love of God. We are committed to loving one another as God has loved us. We seek to be the body of Christ, revealing God's love to the world. We are strengthened by the Holy Spirit as we go from this place. Go in peace.

****A Covenant to Care** is a program sponsored by Health and Welfare Ministries, which encourages congregations and other United Methodist groups to adopt statements covenanting to welcome people with HIV and their loved ones.

The resources below are available from the Service Center, General Board of Global Ministries, 7820 Reading Road, Caller No. 1800, Cincinnati, OH 45222-1800. They are free, except for postage and handling.

AIDS: A Covenant to Care is a statement that declares that your church welcomes people with HIV/AIDS. It can be ordered in two sizes:

- bulletin inserts (English #5072, Spanish #5074 Spanish)
- posters (English #5073, Spanish #5074).

Enabling AIDS Ministries is a flyer that gives information about this Advance Special of The United Methodist Church (#5088).

HIV/AIDS NETWORK FOCUS PAPER ON WORSHIP RESOURCES

INVITATION FOR SUBMISSIONS

In 1995, the Health and Welfare Ministries Program Department, General Board of Global Ministries, The United Methodist Church, plans to feature an HIV/AIDS Network Focus paper focused on worship and HIV/AIDS ministries. We are looking for your original materials (not materials someone else has written and published), such as prayers, litanies, meditations, responsive readings, vignettes, songs, homilies. Short articles on worship and HIV/AIDS ministry will also be considered. Submissions should be 1000 words or less.

We will pay a very small honorarium for each piece published. Our focus paper also has an electronic edition which is uploaded to our own CAM (Computerized AIDS Ministries) bulletin board, the AEGIS network, HNS HIV net, CDC NAC Online, and other electronic information services.

If you are interested in submitting materials, please send them to:

Charles Carnahan
HIV/AIDS Ministries Network
Room 350
475 Riverside Drive
New York, New York 10115

You can also write to the Network and request a sample focus paper or download our online versions from CAM (BBS number 212-222-2135).

In your cover letter, include a short biographical sketch and that you are submitting your work for the focus paper on worship. On each submission, please include your name, address, and telephone, fax, and/or electronic address. Be sure to indicate your correct byline and any copyright notice, if you do not want your work to be in the public domain. If you want your materials returned, please include a SASE.

If we have lots of good material and not enough room in this issue, we may use your submission in a later edition of the focus paper.

DEADLINE FOR SUBMISSIONS: February 1, 1995

WORLD AIDS DAY 1994

Toll Church Bells 14 Times

In an effort to re-focus the public on the impact of the HIV/AIDS pandemic, the AIDS National Interfaith Network is requesting that parishes and religious congregations across all faith communities toll their bells 14 times at 1:40 pm local time on December 1, World AIDS Day. The ringing of the bells will symbolize the 14 years since the first cases of the disease that is now known AIDS were reported.

Bell ringing is symbolic of grief as well as joy. Let this time be an outward sign of our remembrance of those who have died as well as a celebration and recognition of those who continue in compassionate love and service with those living with AIDS/HIV.

Those communities which will ring bells are asked to notify ANIN in writing at 110 Maryland Avenue NW, Room 504, Washington, DC 20002.

A Commitment on HIV/AIDS by People of Faith...*The Council Call*

You have an opportunity to be a part of history this year. For the first time in the 14 years of the pandemic a call is going out -- to religious officials, to the "people in the pews" and to all people of faith across the United States to sign on to *A Commitment on HIV/AIDS by People of Faith...The Council of Religious AIDS Networks* a project of AIDS National Interfaith Network (ANIN).

On World AIDS Day, Thursday, December 1, 1994, ANIN will sponsor a public ceremony at the United Nations to acknowledge and celebrate the endorsements of *The Council Call* received by that date. With your help, we hope to reach hundreds of thousands of people of faith with this important message.

Please make copies of *The Council Call*, if you need to, and disseminate them as widely as possible.

WORLD AIDS DAY

NEWSLETTER



Graphic: M. Langford

AIDS and the Family: *Families take care*

In 1994, the International Year of the Family, the World Health Organization's Global Programme on AIDS (GPA) is marking World AIDS Day under the banner *AIDS and the Family*. Traditional and non-traditional families have a crucial role to play in addressing the HIV/AIDS pandemic.

In the run-up to World AIDS Day – and on 1 December itself – GPA urges the world to focus on how families of all kinds are affected by AIDS, on how they can be more effective in prevention and care,

and on how they can contribute to global efforts against the disease.

For GPA, any group of people linked by feelings of trust, mutual support and a common destiny may be seen as a family. The concept need not be limited to ties of blood, marriage, sexual partnership or adoption. In this light, religious congregations, workers' associations, support groups of people with HIV/AIDS, gangs of street children, circles of drug injectors, collectives of sex workers and networks of governmental, nongovernmental and intergovernmental organizations may all be

regarded as families within the over-arching family of humankind.

Every kind of family should *take care* to protect its members from HIV. And all families should *take care* of those among them who fall ill with AIDS. *Families take care.*

"Families whose bonds are based on love, trust, nurturing and openness are best placed to protect their members from infection and give compassionate care and support to those affected by HIV or AIDS," says Dr Hiroshi Nakajima, Director-General of the World Health Organization.

Families and AIDS

In the mid-1990s, many families worldwide are already disrupted by political upheaval, civil unrest, migration, and other factors. For millions of them, the human immunodeficiency virus is an additional burden and growing threat.

By mid-1994, according to GPA estimates, approaching 14 million women, men and children were living with HIV and AIDS worldwide. The problem would be devastating enough if limited to these people alone, but it also has enormous repercussions on their families. Apart from the huge emotional loss of people dear to them, the families will also face loss of income as breadwinners sicken and die; a loss of care, nurturing and stability; and in rural areas - as AIDS takes its toll on the labour available to till family plots - even a loss of food supply.

Increasingly, it is children who are paying the price of AIDS: not only in the loss of their parents, but also by becoming infected themselves. In Africa, where the pandemic has hit hardest so far, about 700 000 children were born to HIV-positive women just in 1993.

Children born infected face an early death. Those not infected will soon be orphaned. And if grandparents or other relatives cannot or will not step in with the family support needed, the children may have to leave home and fend for

themselves. Not all families have a positive influence on the HIV/AIDS pandemic. Many women and men have been rejected by their families because of their HIV infection. Children have been driven on to the streets by abuse within the

family home. But well-functioning families, who care for their own welfare and communicate openly, are the first line of defence against HIV and among the best sources of care for AIDS.

"It is in families that young people can learn about the importance of safe behaviour and nondiscrimination," says Dr Michael H. Merson, Executive

Director of GPA. "If we all do our utmost within our families of choice - whether they are the people who share our home or those who share our planet - we shall help immeasurably to defeat AIDS in every family". ■



Families take care to protect their members from risks. Above, a family in Nepal. (Photo: WHO/J. Littlewood)

themselves. Such family disintegration *caused* by AIDS can in turn lead to further infections. For children with no family support may find that selling sex on the streets, regardless of its high risk of HIV, is the only way to survive.

What is World AIDS Day?

World AIDS Day - December 1 - is the focus of annual efforts to raise public awareness of HIV/AIDS and spur new and more effective action against the pandemic. It was conceived six years ago after a world summit of health ministers called for a spirit of social tolerance towards people with HIV/AIDS and a greater exchange of information on the subject as a whole.

Each year since 1988, GPA has chosen a different theme for events and activities leading up to World AIDS Day and beyond. The most recent topics have been

"A Community Commitment" (1992) and "Time to Act" (1993).

The number of individuals and organizations involved in World AIDS Day has grown each year, taking GPA's messages of safe sex, compassionate care and anti-discrimination to an ever wider audience. Hundreds of thousands of people around the globe took part in the 1993 World AIDS Day events and activities, which included pop concerts, speeches, marches, seminars, workshops, radio features, street theatre, and special condom promotions.

Information: World AIDS Day, WHO-GPA, 1211 Geneva 27, Switzerland. Tel: (41 22) 791 4765. Fax: (41 22) 791 0107.

Using this newsletter

This is the second *World AIDS Day Newsletter* to be published by GPA in 1994. Through information, ideas and advice, images, articles and personal testimonies, it aims to stimulate discussion and activity on *AIDS and the Family*.

Readers are encouraged to copy the pages in whole or in part, provided reproduction is not for commercial purposes. Signed articles do not necessarily reflect the views of WHO.

Editors: David Lewis, Monika Gehner
Design: Marilyn Langfield

AIDS in Africa

The traditional extended family is withering away in Africa just as its caring influence is most needed to confront HIV and AIDS.

Dr Sandra Anderson and Dr Sam Kalibala of GPA's health care and support unit report here on the role and needs of African families in face of the pandemic.

AIDS is a calamity for humanity whose spread is perpetuated by the other calamities, especially poverty and underdevelopment. The social and medical impact of this disease is worst among underprivileged individuals, families and communities. So it is not by chance that, according to GPA estimates, Sub-Saharan Africa accounted in mid-1994 for more than 10 million of a global total of 16 million adult infections since the pandemic began.

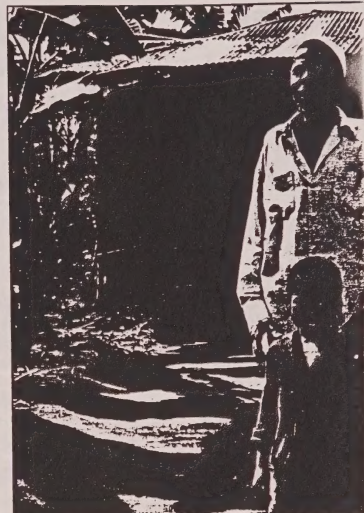
The AIDS epidemic in Africa has highlighted the strength and security of the extended family system in dealing with problems. In some cases, family members have responded by sharing food, shelter and clothing with individuals affected by HIV/AIDS and with their survivors, while medical care, emotional support and school fees have been offered selflessly. In others, family support has fallen short of the needs of people with AIDS and their survivors, so many external supporters and donors have come in and offered generously to supplement the family efforts. In the long term, it is feared that AIDS and other factors are weakening the family's ability to provide care and support to the affected.

Changing societies, changing families

In the changing socioeconomic environment, monetary considerations are taking over from humanitarian and social concerns. Villages are becoming semi-urban settings, and their inhabitants are adopting the more competitive and individualistic lifestyles associated with town life. Economic development is essential in order to reduce poverty, but it is weakening survival concepts of neighbourliness and friendship which were among the strengths of African communities.

In the past, strong unity under a dominant head of the household has been promoted by polygamy, many children, many relatives, respect for elders, clans, arranged marriages and so forth. Such a stable army of a family could offer a form of social security to its members. Today, even where such large families still exist, this security is reduced by the declining monetary strength of the head of the household. Individuals within a family are having to fend for themselves, so they are less available for family chores and, potentially, for AIDS care.

AIDS is particularly devastating because, more than other diseases, it affects people in the prime of their lives. So heads of households are often prevented from developing wealth and a strong family unit. They have less land, fewer cattle and less money – all to the detriment of the family's capacity to cope with a chronic disease financially and socially.



In the United Republic of Tanzania, two young grandparents (Photo: L. Gubb)

The African dilemma

Modern and traditional religions all support the idea of showing kindness to humanity in anticipation of spiritual rewards. Such values are ideal to maintain family and community care for the sick in a traditional rural economy. But the fight against poverty and against such calamities as AIDS requires that African countries must open up to the world and strengthen their economies. Time is precious, and voluntary activities of care cannot be provided for long periods. Calamities, including AIDS itself, have taught individuals to strive and save for the bad times ahead. Even the most sacred and traditional rites of paying respect to the dead are affected, as more people are dying within a short period, and villagers can no longer give with a generous hand to help others.

a family disease



AIDS orphans are brought up by their

Changes in the roles and activities of women, adolescents and children also affect the ability of families to cope with HIV/AIDS.

Women are becoming increasingly involved in economic activity. Greater economic independence can be a boon to AIDS prevention, but it makes women less available for traditional women's work, such as caring for chronically ill husbands, children and brothers. When women fall ill, now at a ratio of 6 women to 5 men in Africa, they are usually cared for by their mothers, sisters or children.

Adolescents, like many women, are sensing a new freedom. In the fight against AIDS, it is desirable for them to become responsible for their sexuality; to be able to negotiate the postponement of sex until older or married, or the practice of safer sex. Yet the right for African youngsters *not* to be

exploited for labour and the right to learn about sexuality bring with them a freedom to opt out of traditional household chores. This will decrease their contribution to care of the sick.

As for **children**, increases in the availability of schooling make them less available to till land, fetch water and firewood, or help the family provide effective care for the sick. In consequence, a newly orphaned niece or nephew is less an extra labour asset than a new drain on family resources.

The way forward

Communities are creating and supporting self-help and locally accessible health and social services, but public health authorities must work hand-in-hand with affected communities and infected individuals to solve the huge problems caused by AIDS and poverty. Instead of providing care and support *to* affected individuals, families and communities, the public health and community development agencies should provide AIDS care and support *with* them.

Communities must increase their own awareness that AIDS and its consequences are family problems. Families will have to create or rejuvenate the traditional support networks among themselves while still maintaining progress gained in advancement of women and children. These networks should assist families to acquire skills and share experiences in care and support activities.

Several plausible arguments suggest that Western aid will decrease due to donor fatigue and other reasons, including economic recession in

the West and the ending of the Cold War. If it does, families will have to take even more responsibility for AIDS care and prevention. In this process, it is vital that AIDS care and prevention should be seen as the responsibility of both men and women.

Nongovernmental organizations have been quick to respond to HIV/AIDS as a real and enormous problem of humanity, and they are invaluable partners in shifting the emphasis from short-term to long-term care and prevention.

Religious groups too, which have long provided a tremendous amount of medical and social assistance, will have to focus on helping *groups* of families in a village, for instance; by offering training in appropriate AIDS care to all, rather than only to families currently affected.

Funding agencies have highlighted AIDS as a priority issue. The World Bank's estimates of the social and economic consequences of the epidemic leave no room for doubt that the most affected communities are the least prepared. Much more effort must be devoted to preparing these communities to handle AIDS as their own continuing chronic problem. Governments and funding agencies alike should widen their agenda to assist whole communities in preparing for care and support of people living with HIV/AIDS and of their survivors. ■

A version of this article appeared in the November-December 1993 edition of World Health, the magazine of the World Health Organization.

Using the media

To reach a large audience with information about AIDS (or any other topic), you must know how to use the media. Newspaper, radio or television coverage can generate country-wide discussion of AIDS issues and broad support for your activities. Here are a few points and tips to bear in mind:

- Newspapers, radio stations and TV channels survive by serving a public need. The information they provide must suit their audience in content and style. So choose your outlet carefully. Articles for young people should be passed to youth magazines or school newspapers; information for workers might be best placed in company newsletters. Where many people can't read, use radio, TV or videos instead of the printed word.
- Approach each sector of the media in the appropriate way. Press releases, news conferences, information kits and personal contacts can reach written and electronic media. Newspapers can also be approached through readers' letters and offers of articles for publication. For TV and radio stations, you could provide audio- or video-cassettes with interviews or images conveying your message.
- Try to present your information attractively. You may be competing for the journalists' attention with a lot of other information and press releases.



AIDS prevention campaigns. For example: "A review by the World Health Organization of studies on sex education in schools reveals no evidence that it leads to earlier or increased sexual activity in young people. In fact, it often encourages young people to delay sexual activity and to practise safer sex when they are sexually active."

- The media may use your news release word for word, not at all, or only as a tip-off for a story. Make sure to include your sources of information and a contact name so that journalists can make their own enquiries or seek further details.
- Make the media aware of what AIDS prevention has achieved, highlighting local success stories where possible.
- Some media slots have more influence than others. "No-one listens to government information broadcasts, so we pay popular disc jockeys to incorporate the messages we have scripted in *their* shows," says Dr Surasing of the Provincial Medical Office in Chiang Mai, Thailand.
- Publicize facts that are likely to break down resistance to frank

discussions. Campaigns based on fear have failed to encourage safer sexual behaviour. A better strategy for the sexually active is to associate condom use with feelings of independence, responsibility or "being cool".

- Media campaigns are much more effective when reinforced by leaflets, posters, videotapes, slides, audio-cassettes, displays, exhibitions, slogans, T-shirts, stickers and other activities or products.
- Give a human face to the epidemic by interviewing people with personal experience of AIDS. Interviews, or feature articles and programmes about people living with HIV, help break down the belief that "AIDS could never happen to me". ■

Ten points for World AIDS Day 1994

AIDS and the Family

1. HIV and AIDS

AIDS (acquired immunodeficiency syndrome) is the late stage of infection with the human immunodeficiency virus (HIV). AIDS can take more than ten years to develop, and most people die within three years of it being diagnosed.

2. Modes of transmission

The vast majority of all HIV infections occur through sexual intercourse. HIV can also be transmitted by infected blood or blood products, by the sharing of contaminated needles, and from an infected woman to her baby before birth, during delivery, or through breast-feeding. It is *not* spread through ordinary social contact.

3. A worldwide problem

More than 16 million adults and one million children had been infected with HIV by mid-1994 since the start of the pandemic, according to estimates by the World Health Organization. Around four million adults and children had developed AIDS. Although Africa has borne the brunt, no continent has been spared. HIV is now spreading fast in Asia and Latin America.

4. Sexual transmission can be prevented

Sexual transmission of HIV can be prevented by abstinence, fidelity between uninfected partners and safer sex, which includes non-penetrative sex and sex with condoms. Children need education about AIDS prevention *before* they become sexually active. Everyone needs easy access to condoms in case of need.

6. The ripple effect on families

Every day, around 6000 people are newly infected with HIV. But several times this number will be newly *affected* by HIV every day through the impact on each infected individual's family and community.

5. The family

The concept of family need not be limited to ties of blood, marriage, sexual partnership or adoption. Any group whose bonds are based on trust, mutual support and a common destiny may be regarded as a family. So religious congregations, workers' associations, support groups of people with HIV/AIDS, gangs of street children, circles of drug injectors, collectives of sex workers and networks of governmental, nongovernmental and intergovernmental organizations may all be seen as families within the over-arching family of humankind.

7. An extra threat in the 1990s

Many families in the 1990s are disrupted by political upheaval, civil unrest, migration, and other factors. For millions of them, HIV is an extra threat. If a breadwinner falls ill with AIDS, they face losses of income and sometimes food supply.

8. An additional burden for women

Nearly half of all newly infected adults are women. But as women are the traditional care-givers, even *uninfected* women are affected by HIV when it enters a family. Women widowed by AIDS are often rejected and stripped of their belongings.

9. Children pay a growing price

Increasingly, children are paying the price of AIDS – either by being infected themselves or through the effect of AIDS on other family members. They may lose their parents and have to live on the streets if other relatives cannot or do not step in with support.

10. Families take care

All families, traditional or non-traditional, can help stop AIDS spreading by making sure that their members understand – and act on – the facts about HIV and safer behaviour. And if one of their members *does* fall ill with AIDS, families are often the best source of compassionate care and support.



Families take care

New From UFMCC Church Services

Christian Caring

"If there ever was a need for a ministry of hope, healing, and comfort, it is with those touched by this disease."

Establishing HIV/AIDS Ministry in the Local Church
A Manual for Pastors and Church Leaders by Paul A. Tucker

When HIV/AIDS Comes to Your Church...

What do you do to put hands and feet to your prayers? How can your church follow the example of Jesus?

CHRISTIAN CARING

A Manual for Pastors and Church Leaders
by Reverend Paul Tucker

This manual suggests four different models of HIV/AIDS ministry for the local church, dealing with conditions ranging from asymptomatic to debilitation. Each of the models suggested in this useful guide has been tested in congregations that have active AIDS ministries.

Mail completed form to UFMCC Church Services, 5300 Santa Monica Blvd., Suite 304, Los Angeles, CA 90029.

Please rush me a copy of CHRISTIAN CARING

Name _____

Address _____

City, State, Prov _____

Zip, Postal Code _____

Personal orders placed by individuals must be prepaid. For churches and organizations, orders to be billed will be charged \$2 handling plus shipping costs; prepaid orders will be charged \$2 shipping/handling per book.

Number of books _____ x \$8.00 _____

Subtotal _____

Sales Tax (CA res. add 8.25%) _____

Shipping/Handling \$2/book _____

Total Amount Due _____

All payments must be made in U.S. Dollars.

___ Enclosed is my check/money order

___ Please charge to my Visa/Mastercard

No. _____ Exp. _____

Signature _____

